

**Promoting Parent-Therapist Collaboration in Intensive Behavioural Intervention Programs:
Exploring Strategies to Improve Teamwork**

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Abstract

This qualitative study investigated senior level staff (Senior Therapists), front-line staff (Instructor Therapists), and parent perspectives on parent-therapist collaboration within Intensive Behavioural Intervention settings. Two senior staff interviews, two parent interviews, and a focus group with therapists were conducted to examine how parents and therapists currently interact within IBI settings, parent and therapist expectations of each other, factors that promote and barriers that impede parent-therapist collaboration, and how parent-therapist collaboration might be improved. A constant comparative analysis by question within and across cases revealed five prominent themes of 'Role Definition', 'Perspective-taking/Empathy', 'Trust', 'Open Communication', and 'Consistency'. Additional similarities and differences were discovered between parent and therapist perspectives such as the need for clear parent-professional boundaries, the importance of maintaining client privacy, and respect. Implications of the findings and suggestions for future research are discussed.

Promoting Parent-Therapist Collaboration in Intensive Behavioural Intervention

Programs: Exploring Strategies to Improve Teamwork

Intensive behavioural intervention (IBI) plays an important role in the lives of families of young children with autism. As part of this treatment approach, the child, parents, and therapist form a necessary triumvirate. The perspective of each member should be considered during the development and evaluation of treatment. Parents of children with autism and Instructor Therapists (ITs), who provide one-on-one training, are expected to aid in the acquisition, generalization, and maintenance of skills taught to these children (Solish & Perry, 2008; Spann, Kohler, & Soensken, 2003). Minimal research however, has been conducted in which both parents and therapists are consulted to examine the expectations each have of one another, how collaboration is promoted, and how this relationship can be improved for the benefit of the parents, therapist, and child.

Collaboration is defined as a way of working together to achieve a common goal (Dinnebeil, Hale, & Rule, 1999) which involves a partnership or relationship that reflects high levels of mutual respect, openness, trust, and shared responsibility. Adopting a collaborative approach to behaviour support entails designing and implementing treatments with those who have the most regular direct contact with the child, those who are most familiar with the child's background, and those who are most highly motivated to be involved in the intervention process (Dunlap & Fox, 2007). Such a partnership requires a "...clear and strong commitment by both parties, a shared vision, trust and open communication, mutual respect, and an understanding of each party's circumstances and roles" (Lucyshyn, Dunlap, & Albin, 2002, p. 161).

For young children with autism participating in early intervention services, parent-therapist collaboration is an essential component of effective treatment and service delivery

(Case, 2001; Dunlap & Fox, 2007; Nevas & Farber, 1999). Collaborative efforts have the potential to result in enduring behaviour change, improved quality of life for the child and his/her family, higher levels of parental satisfaction, and improved parenting strategies (Brookman-Frazee, Stahmer, Baker-Ericzen, & Tsai, 2006; Marshall & Mirenda, 2002; Spann, Kohler, & Soensken, 2003). Lack of collaboration and poor communication can result in parents feeling as if their concerns are being ignored, parents and professionals not following through with scheduled tasks, parents and professionals having difficulty expressing their concerns to one another, and both having difficulty evaluating each others' participation (Hanna & Rodger, 2002).

When it comes to the level of parental involvement in programming and the promotion of generalization of gains made in therapy for children with autism, frustration arises when parents and therapists do not communicate their needs and expectations. It is as a result of this disconnect between parents and professionals/paraprofessionals that a re-examination of the role and expectations of parents, as well as the support that they require, needs to occur. To begin to do so, the current study was designed to gain qualitative insight into how parents and therapists interact, how collaboration is promoted between the two, and how current practices might be improved, in order to inform future training opportunities for therapists and parents, IBI policy, and day-to-day transfer of skills from therapy to home and community settings.

Presently there is not much research that describes how parents and therapists interact within IBI settings and whether this interaction is beneficial to clients, parents, or therapists. The goal of this research was therefore to investigate relationships between parents of children with autism who have received or are currently receiving IBI services and Instructor Therapists (ITs) to establish a framework for understanding and evaluating parent-therapist dynamics. Past

research examining parent perspectives on special education suggests there is a mismatch between parental expectations of teachers and the requirements of professional practice which values objective involvement (Hess, Molina, & Kozleski, 2006). Parent perspectives have been routinely examined (Dunlap & Fox, 2007; Petr & Barney, 1993; Renty & Roeyers, 2005; Thompson, 1998; Whitaker, 2002), but few studies have investigated the views of therapists (Able-Boone, Goodwin, Sandall, Gordon & Martin, 1992; Sperry, Whaley, Shaw, & Brame, 1999) and, to the researchers' knowledge, no study has examined both perspectives in a joint discussion. Unfortunately, due to issues that are taken up in the discussion, a joint discussion was not possible for this study. The implications of this and recommendations for future attempts to have a joint discussion are considered.

By interviewing parents and therapists in interactive focus group settings, participants were provided an opportunity to share their experiences in an accepting environment, with individuals who valued their opinions (Andonian, 2008; Brotherson, 1994; Morgan, 1993). Investigating the way in which parent-therapist relationships function (i.e., what works and what does not work) is also important for informing future research on parent training programs, therapist training, and how to promote collaboration between the two. Because significant discrepancies between parents' and educators' expectations could be detrimental to the child, it is important to assess whether incompatible ideas exist between these two groups (Ivey, 2004). Future research can then expand on the information obtained in these focus groups to evaluate current practice and to develop programs informed by the parent-therapist perspective. Information gathered from a supervisory level (Senior Therapists), front-line staff (ITs), and parents, who have had a variety experiences with IBI, represents a unique and comprehensive

start to optimizing service delivery by incorporating the perspectives of the primary stakeholders in the intervention process for a child with autism.

Children with autism are more likely to have better adult outcomes if they are provided the opportunity to master functional daily living skills in a variety of environments (Carothers & Taylor, 2004). To work toward the maintenance and generalization of skills learned in therapy, it is crucial that parents and therapists communicate on a regular basis. To begin to address this gap in service provision, research is needed to better understand what factors influence parent-therapist relationships and what *both* parties would like to see improved.

Literature Review

Intensive Behavioural Intervention (IBI), founded on the principles of Applied Behaviour Analysis (ABA), has been adopted as the treatment of choice for children with autism (Eikeseth, Smith, Jahr, & Eldevik, 2007; McEachin, Smith, & Lovaas, 1993; Remington et al., 2007). Numerous studies have demonstrated its effectiveness in teaching new skills and reducing maladaptive behaviours in young children with autism (Lovaas, 1987; Sallows & Graupner, 2005). The focus of research is now expanding to investigate the specific components of early intervention that are most effective and the level of family involvement that can positively enhance programming. Additional research about the family's role in IBI, however, is still needed (Solish & Perry, 2008).

IBI teams typically consist of a Supervisor/Senior Therapist, a lead therapist and one or more other Instructor Therapists (ITs). ITs are the front-line workers who work directly with the child and implement the programs developed by the supervisory team. The Supervisor/Senior Therapist works in conjunction with a Clinical Supervisor who oversees the program and reports back to a Clinical Director. Individual programs are developed and monitored by the Senior

Therapist and a consulting Clinical Supervisor/Psychologist who reports back to a Clinical Director. The hierarchical structure of this program provides a complex environment for researchers to examine. How each level relates to one another and how each individual understands and fulfills his or her role in this hierarchy can have important implications for service delivery. Information about parent involvement and parent-professional collaboration is beneficial for service providers and staff and is necessary to improve the services provided for the benefit of the child and the family. It was therefore essential that steps be taken to seek out the perspectives of parents and therapists.

Parent Perspective

Families of children with autism face numerous challenges. Plienis, Robbins, and Dunlap (1988) reported on parent adjustment and family stress for families of young children with autism and outlined family recreation, finances, and parental emotional well-being as negatively affected by the demands and difficulties associated with raising a child with autism. Fleischmann (2004) examined narratives published on the Internet by parents of children with autism and revealed that a wide range of challenges are associated with coping with their child and the intensive treatment involved. Parents expressed having difficulty finding sufficient support, experiencing bouts of self-blame regarding their child's disorder, feeling socially isolated, and in need of emotional support. Furthermore, interpersonal relationships with immediate and extended family members and community are often strained (Case, 2001; Dunlap & Fox, 2007; Fleischmann, 2004; Plienis, Robbins, & Dunlap, 1988).

Parents are responsible for initiating therapy, are necessary partners for the continuation of therapy and maintenance of gains, and can affect the progress of the child throughout treatment. Because parents can help provide background information on the child (e.g.,

developmental milestones, behaviour across settings, strengths/skill deficits), can help monitor changes in the child as treatment occurs, and can adjust the home environment to promote treatment successes, therapists need parental input (Nevas & Farber, 1999). It is therefore imperative that parents' perspectives be incorporated into treatment development in order to optimize the experience for the child.

To begin to determine what the perspectives of parents within IBI settings are and how to use this information to better serve the family and child, five mothers were consulted about their experiences with IBI. As the findings and recommendations for practice and future research will indicate, this study serves as a unique start to uncovering the relevant issues to parents and families in this setting and highlights the need to promote open discussion with parents on issues that directly affect their child and families.

Therapist Perspective

Although less reported on, therapists also experience pressures that may affect parent-therapist collaboration. As services are provided to families who are, according to Perry et al. (2008) "...socioeconomically, linguistically, culturally, and psychosocially" diverse, and the Ontario program is designed to provide IBI to children who would be considered to be at the more severe end of the autism spectrum (Perry, 2002), therapists are required to provide services for a very heterogeneous population. This often requires the ability to be sensitive to the needs of parents, to provide positive feedback, to be flexible, and to respond to rapid changes in families (Bjorck-Akesson & Granlund, 1995). Annual staff turnover rates in 2006 for mental health and human service agencies were estimated at 25 to excess of 50% of qualified therapists (Greeson, Guo, Barth, Hurley, & Sisson, 2009), suggesting the role of a therapist may be demanding and unfulfilling for many. It is therefore important to examine what barriers therapists perceive in

their workplace that may affect their ability to collaborate with parents and to provide them with an outlet for sharing their experiences with others.

A wide variety of studies have examined parent perspectives in regards to service provision (Baxter, 1989; Renty & Roeyers, 2005), and parent-professional collaboration (Case, 2001; Hanna & Rodger, 2002), but few have extended their research to encompass the therapist perspective as well. Research seeking the therapist perspective has been relegated to their perceptions on family-centered approaches to services (Able-Boone et al., 1992; Bailey, Palsha, & Simeonsson, 1991; Raghavendra, Murchland, Bentley, Wake-Dyster, & Lyons, 2007) and parent involvement in their child's treatment (Dunlap & Fox, 2007; Solish & Perry, 2008).

The majority of studies devoted to examining parent-therapist collaboration have done so from a quantitative perspective gathering data from questionnaire research (Able-Boone et al., 1992; Case, 2001; Ivey, 2004; Raghavendra et al., 2007; Solish & Perry, 2008), theoretical and literature-driven research (Alexander & Dore, 1999; Hanna & Rodger, 2002; McLoughlin & Strenecky, 1978; Osher & Osher, 2002), or parent perspective alone (Baxter, 1989; Benson, Karlof, & Siperstein, 2008; Petr & Barney, 1993). While these are important issues to investigate, it is very evident that a significant gap in the understanding of parent-therapist relationships exists by neglecting to consult therapists about their experiences. Front-line workers, who spend significant amounts of time (i.e., 20 – 40 hours per week) interacting with and teaching the children of these parents, are rarely consulted about their impressions of parent-therapist collaboration, their expectations of parents, or barriers to collaboration that they encounter.

Sperry et al (1999), as part of two national forums in the United States on issues in early intervention and preschool services, consulted parents and service providers about their hopes,

expectations, barriers, and effective practices in reference to service delivery. Of the 22 service providers who participated, a number were professionals (e.g., psychologist, speech/language pathologist) and service coordinators (e.g., administrator, project coordinator). A few voices were represented by educators and a technical assistant, but none were described as therapists who provide early intervention services. Therapists appear to be an untapped resource regarding parent-therapist collaboration and the potential exists to determine how their perspective may contribute to the knowledge of such relationships and the relative acceptance and effectiveness of this interaction within IBI settings.

Seven therapists who have worked, or are currently working, within IBI settings were invited to reflect on their experiences in IBI and share their perspectives on parent-therapist collaboration. From this, as the findings and discussion will address in detail, knowledge has been gained about what therapists understand their role to be, factors that promote and impede collaboration with parents, and suggestions for improving these important relationships. Therapists indicated that they often feel undervalued in their role suggesting seeking their input may have been a validating experience for those who participated.

A variety of issues surround service provision for young children with autism (Ivey, 2004; Renty & Roeyers, 2005; Sperry et al., 1999). In examining the experiences and perspectives of parents and therapists using and providing these services, three aspects of the literature are worthy of consideration: parental involvement, parent-professional collaboration, and challenges associated with service provision.

Parental Involvement

Research supports the involvement of parents in planning and implementing treatment (Benson, Karlof & Sipperstein, 2008; Solish & Perry, 2008; Spann et al., 2003) and the

importance of fostering communication between parents and service providers (Case, 2001; Renty & Roeyers, 2005). Interview data collected by Benson, Karlof, and Siperstein in 2008 to evaluate maternal involvement in the education of their young children with autism found that what schools do and do not do plays a critical role in the extent to which parents participate in the education of their children. The greater the extent to which teachers encouraged, provided opportunities for, and actively supported parental involvement, the more involved parents were in their child's education. Parent participation in special education services can lead to more positive outcomes for children with special needs and promotes the generalization and maintenance of treatment gains (Spann et al., 2003). Because parents spend a great deal of time with their children they can often provide unique insights about the needs of their child and their family.

Parental involvement however, is not always viewed positively. Spann et al., (2003) described negative perceptions held by educators such as families not being credible sources of information, being dysfunctional, or even confrontational. Conversely, some educators felt as if too many demands were being placed on parents (Spann et al., 2003) suggesting there is still reservation in involving parents as partners.

A multivariate analysis of parental involvement, conducted by Solish and Perry (2008), examined parent self-efficacy, knowledge of autism and IBI, belief in IBI, perception of child progress, and stress as predictors of parental involvement. The study concluded that greater self-efficacy, knowledge of, and belief in IBI, were related to higher levels of parent involvement. Comparison of responses provided by parents and those provided by therapists revealed little overlap suggesting a need to further examine parent and therapist perspectives on parental involvement in IBI and the factors that predict it. Solish and Perry (2008) did point out that it is

unrealistic to intervene only at the level of parental involvement by encouraging parents to attend meetings, promote generalization, and communicate with therapists. The authors reported a need to target the predictors of involvement to effectively alter levels of parental involvement. As not all of the factors examined in this study were found to be significantly correlated to parental involvement, and parent responses compared to therapist responses were quite variable, a need remains to examine parental involvement from a qualitative perspective to obtain detailed descriptions of this component of IBI and what factors parents and therapists believe are the most relevant to parental involvement.

Parent-Professional Collaboration

Parents and therapists are the front-line caregivers and workers for children with autism. Substantial research has been conducted to examine the relationship between parents and professionals of children with challenging behaviours (Kazdin, Whitely, & Marciano, 2006), disabilities (Hess et al., 2006; Petr & Barney, 2006), and mental health disorders (Andonian, 2008). Kazdin, Whitely, and Marciano (2006), in their investigation of parent-therapist alliances in the treatment of children with oppositional, aggressive, and antisocial behaviour, determined that such alliances were related to increased therapeutic change in the children and improvements in parenting skills and interactions at home. Collaboration between parents and professionals has also been documented to increase the likelihood that a family will continue intervention (Marshall & Mirenda, 2002). Families are more likely to be involved in trying to accomplish the goals set for their child if a parent-professional relationship exists and both the family and professionals collaborate in the formation of the goals (Renty & Roeyers, 2005).

Previous research has also examined the nature of parent-professional relationships (Dunlap & Fox, 2007; Marshall & Mirenda, 2002) and parent-educator relationships within

school settings (Hess et al., 2006; Spann et al., 2003; Stoner & Angell, 2006). Marshall and Mirenda (2002) described a partnership between a family of a child with autism and severe challenging behaviours and a behavioural consultant. The authors concluded that relating to families as colleagues, recognizing family expertise, and the need for all parties to cooperate on a common goal were the most beneficial practices for recognizing and appreciating each others' perspectives and understanding the needs of the child. Similarly, Dunlap and Fox (1999) argued that comprehensive family support is a necessary component for intervention that is most effective when it is established early in the experience, is developed collaboratively with the parents, and is designed to provide stability and consistency across time and settings.

Challenges in Service Provision

Barriers to communication between parents and therapists are likely to inhibit the child's ability to benefit from treatment (Nevas & Farber, 1999) indicating the need to identify and understand what these barriers may be and how they can be overcome.

Traditional roles of parents and professionals. Studies have shown that parents and service providers have different opinions about the effectiveness of early intervention and the nature of collaborative relationships (Spann et al., 2003). In examining these perspectives it is important to understand the differences between the roles of the parent and the roles of the service provider and how these interact. "Parents are emotionally involved with and committed to their child. Conversely, professionals are often expected to maintain a measure of professional distance and avoid emotional involvement with the family" (Sperry et al., 1999, p. 18).

Renty and Roeyers (2005) pointed out that relationships between parents and professionals in the past have often been paternalistic. Osher and Osher (2002), in their overview of the move toward collaboration with families of children and youth with emotional

disturbances, discussed the provider-driven paradigm in which professionals and agencies are considered to be the central figure in problem solving and decision-making. Problems that surface when professionals or agencies have this orientation to service provision result from expectations that consumers should comply with the 'experts' suggestions and also when parents themselves believe the expertise of the professional is definitive. Professionals are assumed to possess the knowledge and skills to identify a problem, design a plan to solve it, and implement the appropriate procedures to meet this goal within the confines of professionalism and agency procedure (Osher & Osher, 2002). It is not clear however, what expectations parents and ITs have of one another or if problems arise from these expectations not being met.

Mismatched expectations and role confusion, particularly in situations where the parents may be heavily involved in implementing treatment (e.g., trying to be a therapist for their child at home) or therapists are closely involved with the family (e.g., providing in-home therapy and respite), can jeopardize the effectiveness of treatment by confusing responsibilities and blurring accountability. Unfortunately, whether the crossing of such lines occurs has not been clearly documented, nor have the opinions of parents and therapists from both settings been examined simultaneously. Whether the traditional role of the parent and professional is observable in IBI settings and whether certain stressors are more apparent than others has yet to be determined.

Parents may also differ in the level of involvement they choose to have in their child's treatment (Hanna & Rodger, 2002) suggesting it is important for therapists to be aware of what shape this involvement will take and how to make the most of it. A study by Thompson (1998) examining mothers' perceptions of early intervention services reported that mothers felt therapists did not consider other demands that were placed on them in addition to those related to therapy. It is not clear however, what training is provided to enable therapists to accommodate

the needs of parents or to communicate the appropriate information to the parents to satisfy the expectations of both parties.

Bjorck-Akesson and Granlund (1995), in a Swedish study of parent and professional perceptions of family involvement in assessment and intervention, aptly stated: “To work well in collaboration with families, professionals need knowledge in system theory applied to families, in communicating with families and developing rapport, in determining family needs and strengths, and in giving proper information to families”. Research into the expectations parents and therapists have of one another will thus help to ascertain whether additional training for parents and therapists may ameliorate this potential disconnect or if a different approach to parent-therapist interaction and relationship development should be explored.

Systems barriers. Numerous barriers that impede the quality of parent-professional relationships have been documented which could conceivably apply to the parent-therapist relationship within IBI. Hanna and Rodger (2002) outline that beyond the traditional view of professionals assuming hierarchical positions over parents, differences between past experiences, knowledge, cultural values, and personalities may inhibit parents and occupational therapists from forming an equal partnership. Additional research on parent and therapist views on collaboration in occupational therapy have drawn attention to time and schedule inflexibility, as well as the lack of experience and education therapists have related to working with families (Thompson, 1998). Difficulties surrounding lack of resources (e.g., time, professionals), administrative policies or routines, and pre-established patterns of service provision (e.g., fixed guidelines for collaborating with others) can also serve as barriers to collaboration (Bjorck-Akesson & Granlund, 1995). Parents and therapists of children with autism may also be affected by such factors and more.

Hanna and Rodger (2002) reported that occupational therapists and other health professionals are not always confident in their ability to competently work with parents or to manage parents' feelings. Such reservations raise the issue of training and whether staff of IBI programs feel competent when interacting with families. There is also the question of the level of expertise parents expect therapists to have when interacting with families. Bjorck-Akesson and Granlund (1995) suggested that in-service training in family-focused skills for early childhood interventionists is obviously needed. Their study, conducted in Sweden, involved asking 139 professionals on habilitation teams and 73 parents of children with disabilities to rate their current habilitation program on issues regarding family involvement (e.g., decisions about the child assessment process, parent participation in team meetings, and decisions about child goals and services). Participants were also asked to identify barriers that contribute to the discrepancy between ideal and typical practice. The results highlighted various differences in parent and professional perceptions of services and common system barriers such as lack of resources, administrative policies, financial support, and staff that impede collaboration.

An interesting limitation, however, acknowledged by the authors was attributed to the different experiences of the habilitation process professionals had in relation to those of the parents. The experiences of the professionals represented a second-hand perspective, or more general overview of experiences compared to the specific, first-hand experiences of parents. By indicating parents and professionals have quantitatively and qualitatively different experiences suggests it may be worthwhile to examine first-hand experiences of therapists who are direct service providers and who may have more in common with parents as they are both interacting with the child on a regular basis. Seeking the input of parents and therapists on training received

and ideas for how to improve collaboration with one another will delineate whether either party feels this is an important factor to examine in further detail.

Personal Barriers. Difficulties from a personal perspective may also be reflected in parents' lack of knowledge or skill, negative attitudes (e.g., parent is unwilling to take on more responsibility), lack of resources or financial support, or other family characteristics that may impede their ability to participate, such as living in a rural area (Bjorck-Akesson & Granlund, 1995). These barriers may impinge on the formation of collaborative relationships between parents and therapists by reducing the amount of time they have to interact with one another as well as the quality of these interactions. Understanding what personal barriers affect the development of parent-therapist relationships in IBI can help service providers prepare to address these concerns through staff training or by directing families to outside resources that are qualified to offer the support a family might need.

The researcher's preliminary review of the literature revealed that parent involvement, parent-professional collaboration, and challenges to service provision may be relevant to parent-therapist collaboration in IBI. Following the analysis, issues such as breadth of responsibility and parent-professional boundaries were also determined to be important to consider. As a result, the researcher will take up these concerns in the Discussion to provide a context for the inclusion of these topics.

Research Questions

The goal of this research therefore, was to obtain a detailed qualitative account of the experiences parents and therapists have had with one another and to determine what kind of factors promote and impede collaboration in order to pinpoint areas for improvement. Two interviews with senior level staff, two interviews with parents, and a focus group with therapists

were conducted to examine these issues and to identify points of agreement and disagreement among the groups who comprise the intervention and support teams for children with autism receiving IBI. Questions explored included: 1) How do parents and therapists currently interact within the context of IBI services? 2) What are parent and therapist expectations of each other, 3) What are the factors that promote parent-therapist collaboration? 4) What does each group perceive as the barriers to open collaboration? and 5) How might the parent-therapist relationship be improved?

Method

Ethics

The researcher submitted an application for the ethical review of research involving human participants to the Brock University Research Ethics Board (REB). The project received ethics clearance for the period of July 23, 2009 to April 30, 2010 (File # 08-365). One modification was submitted to the REB committee on September 9, 2010 to request permission to extend recruitment to local agencies and distribute posters at the Ontario Association for Applied Behaviour Analysis Annual Conference in November, 2009. This modification was accepted on September 14, 2009. No participants were contacted or interviewed prior to ethics clearance.

Qualitative Methodology

IBI settings represent extremely enriched environments in which a variety of perspectives can be explored to better understand how such programs work and where to focus future research efforts. Research on the IBI programming initiative in Ontario has been limited to a quantitative perspective primarily for the purposes of evaluating program efficacy and effectiveness. Expanding this research base to include the qualitative perspectives of the major stakeholders

(parents) and providers of services (therapists) can provide a fresh outlook on the quality of services provided from an individual and collaborative perspective. Seeking separate input from parents, therapists, and supervisors can inform service providers of current levels of collaboration and the expectations parents and therapists have for each other.

“Qualitative measures describe the experiences of people in depth. The data are open-ended in order to find out what people’s lives, experiences, and interactions mean to them in their own terms” (Patton, 1980, p. 22). From the experiences of parents and therapists involved in IBI, an understanding of parent-therapist collaboration and the current needs of both can be derived which represents the struggles and accomplishments of both parties as they attempt to do what is best for the child. This study provided participants an opportunity to recognize that their experiences are valued and meaningful and that they are helpful in informing others how parents and therapists interact and why this interaction is important.

Focus Groups

Focus groups are a means for gathering high-quality, usable information capturing the collective voice of participants (Andonian, 2008). This method allows the researcher to obtain more information than is typically available in survey research and enables participant interaction. The development of a set of questions designed to elicit rich information and encourage interaction is typically based on past research of the views of participants (Morgan, 1993). As the views of both parents and therapists of children with autism have been meagerly researched, conducting focus groups with this population will serve to increase the understanding of parent-therapist dynamics and most importantly how to improve these relationships for the benefit of the child. Conducting a variety of interviews across three groups who are intimately tied to the process of providing and receiving services in IBI allowed the researcher to gather

numerous types of data to aid in confirmability and probe emerging themes (Stoner & Angell, 2006). This tiered process of data collection will serve to increase the amount and quality of information obtained by interviewing several team members knowledgeable of the child, the parent-therapist relationship, and IBI, and will increase its validity by confirming accuracy and reliability across participants.

Previous studies involving focus groups with parents and professionals have recommended this approach as a way to empower participants by validating their opinions and experiences, to inform collaborative care projects, and to break down barriers that prevent progress (Andonian, 2006). Such an approach is also useful for collecting feedback on effective practices and determining areas that may need further development (Patton, 1990). Qualitative research can elicit multiple perspectives from those who live and work with children with autism, improve our understanding of the diverse issues that parents and service providers face, and present detailed accounts of experiences with IBI that can be helpful for informing and assessing program outcomes (Brotherson, 1994).

As a data collection method, focus groups have the potential to benefit both the researcher and the participants. This holistic approach to understanding a phenomenon assumes that describing and understanding the context of a service is necessary for understanding the program (Patton, 1990). By asking open-ended questions the researcher can come to understand experiences by organizing patterns and analyzing important dimensions that emerge throughout the discussion. This enables the researcher to get close to topics of interest using direct personal contact and developing a sense of social intimacy and confidentiality with the participants (Patton, 1990).

Setting

As stated in the Ministry of Children and Youth Services (MCYS) Pre-school Intervention Program For Children with Autism Program Guidelines (2004), the goal of the program is to “...provide high quality, evidence-based intensive behavioural intervention and associated services, such as Child and Family Supports and Transition Services for children with autism, that are coordinated with other services that children and their families are receiving”. Rising prevalence rates of autism indicate an increasing need for services to meet the needs of these children and their families (Stahmer, 2007). As IBI is an evidence-based intervention funded by the federal government, and its services are being accessed by families from a wide variety of backgrounds, information pertaining to the nature and quality of this provision can be beneficial to numerous stakeholders.

Presently, minimal information is available to describe the experiences of parents and therapists involved in IBI. The way in which parents and therapists interact in these settings may provide useful information about positive practices and areas that need improvement. Conducting focus groups with parents and therapists from both of these settings will aid in the description of parent-therapist dynamics specific to IBI for children with autism and how collaboration between parents and therapists can be fostered to optimize service provision in either setting a child might be receiving treatment.

Measures

Question Development. To examine parent-therapist collaboration from a qualitative perspective, the researcher developed a variety of questions designed to describe parent-therapist collaboration, the expectations parents and therapists have of each other, and how to improve such collaboration. The questions were developed according to Patton’s (1980) six basic types of questions: experience/behaviour questions, opinion/value questions, feeling questions,

knowledge questions, sensory questions, and background/demographic questions. Probes and follow-up questions were prepared in advance to be used as necessary (at the discretion of the moderator) to deepen the response to a question and thus increase the richness of the data collected (Patton, 1980). The researcher chose to include open-ended questions for all of the participants in an attempt to gain a better understanding of parent-therapist collaboration within IBI and which future directions such programs should take to accommodate the needs of both therapists and parents.

Focus group script. The questions were then embedded in a written script (Appendix A) formulated based on previous focus group research (Bjorck-Akesson & Granlund, 2005; Brotherson, 1994). The basic format of the script included a welcome and introductions, overview of the topic, ground rules for the interview, the questions and probes for each group, and a conclusion. The script was used as a guide for each semi-structured focus group and served as a protocol to ensure consistency across sessions.

Demographics. A short questionnaire was designed for each group to elicit information useful in describing the sample of participants interviewed. The parent questionnaire included 16 questions regarding education, relationship to child, age of child, sex of child, and treatments currently received for the child (Appendix B). Supervisor and therapist information included ten questions related to education, years of clinical experience, length of time working in IBI with children with autism, and additional clinical experience that may inform their perspective (Appendix C).

Recruitment

A sample of 16 participants (four STs, five parents, and seven ITs) was recruited for the current study. Senior level staff were recruited by word-of-mouth and personal contact. Contact

by phone and e-mail was used to determine the availability of each potential participant and all four individuals who expressed interest were accepted to participate in the study. Therapists were recruited in a similar fashion due to the ethical restrictions associated with recruiting through an agency. The researcher circulated a flyer (Appendix D) at a local Autism Ontario chapter and an ST informed Instructor Therapists of the opportunity to participate. E-mail from three ITs who agreed to participate and agreed to be contacted by the researcher, were followed by contact from the researcher to explain the details of the study and confirm the therapist's interest and availability. Four additional therapists were also referred to the researcher through e-mail and were willing and available to participate. One therapist was too busy to attend. This resulted in a total of seven therapists who participated in one focus group discussion.

Parents in the Niagara region were recruited through Brock University's Autism Spectrum Disorder Summer Movement Camp and the Special Needs Activity Program (SNAP). The director of these programs was contacted to obtain permission to recruit participants through her programs (Appendix E). Ongoingly, parent who enroll their children in these programs are informed of the possibility of being contacted for research opportunities. The camp profiles of ten children indicated that they had received IBI services and the parents of each were personally contacted via telephone and/or e-mail to explain the purpose of the study and to ask if participating in a focus group discussion would be of interest to them. Each family expressed interest in participating, but one family was not eligible because their child had only been on the waitlist for IBI and not enrolled in a program. After eligibility was determined, each parent was contacted to request their availability. Nine parents confirmed their interest in participating, but two of these parents then indicated they were not available at this time. Two dates for the parent

focus group were then chosen based on the schedules of the seven parents who indicated their availability. From the seven, three confirmed they could attend.

A participant who took part in the therapist focus group also forwarded a flyer to a parent out of town whom she thought might be interested in taking part. This parent contacted the researcher and expressed great interest in participating. She was originally asked to participate via Skype in the Niagara parent group but, due to a scheduling conflict, this was not feasible. After the researcher suggested going to her town to meet with her, she offered to invite some other parents she knew to participate. Two other parents were recruited as a result. A total of five parents were interviewed for the study.

Due to the difficulty finding participants and scheduling a time that was convenient for all, random selection of participants did not occur. All participants who expressed interest were offered the opportunity to take part and the researcher provided multiple dates, times, and locations to ensure each had equal opportunity to participate.

Sample

The perspectives of four supervisory level staff who work in IBI settings – five parents of children with autism who have received or are currently receiving IBI services for their children, and seven therapists who have worked, or are currently working – in an IBI setting were consulted about their experiences with IBI.

Supervisory Level

Four Senior Therapists (STs) who currently work at three different agencies in the Niagara region were interviewed about their thoughts and experiences with parent-therapist collaboration. All participants were female and the average age of participants was 44.

Participants have been in the position of ST for, on average, 5.13 years and estimated that they interact with the parents of one client approximately 1.3 hours per week.

Parents

Five parents, two who have children who have previously received services in IBI, and three parents with children currently receiving IBI took part in this study. Two parents have two children with autism – both of whom have received services. All of the parent participants were married, Caucasian females with a child (or children) who have received IBI services for an average of 1.5 years. Parents estimated spending on average, 4.66 hours a week interacting with their child's therapist. This level of interaction ranged from 30 minutes per week to 10.5 hours per week. Parents noted including time spent in generalization sessions, team meetings, and before and after session discussion time in these estimates.

Therapists

Seven therapists, three who are currently Instructor Therapists (ITs) for a regional IBI program in Ontario and four who were previously employed as ITs in different programs across Ontario and Canada, participated in the focus group discussion. One IT was employed in a rural area and all but one (who worked for a private agency) were employed within a regional program. All of the participants were female and the average age of participants was 25.43. The average number of years participants reported as being ITs was 3.64 and estimated 21.43 minutes per day were spent interacting with the parents of each client.

Procedure

Supervisory Level Interviews

Due to scheduling difficulty, two separate interviews (instead of one focus group) were conducted with senior level staff.

Interview 1

Two Senior Therapists (STs) visited Brock University to participate in a discussion about parent-therapist collaboration in IBI in January 2010 for 90 minutes. The researcher met the participants on arrival and provided each with a free parking pass for their vehicles. Upon arrival in the meeting room, participants were seated beside one another and across from the researcher and Research Assistant (RA) who was present to monitor the electronic equipment and record additional field notes. The RA was required to sign a General Statement of Confidentiality (Appendix F) prior to attending the interview. Participants were introduced to each other, as well as to the RA and then each participant was provided with two copies of the Supervisor Informed Consent Forms (Appendix G) and advised to feel free to ask any questions they might have. They were reminded that if they were uncomfortable with any part of the study they could leave then, or at any point during the study, with no repercussions. A copy of the informed consent was retained for the researcher's records and the other provided to the participant. Participants did not have any questions during the informed consent process.

Following informed consent, participants were asked to complete a short demographics questionnaire and the researcher fielded any questions participants had at that time. After each participant completed and returned the questionnaire, the researcher proceeded to introduce herself, provide an overview of the research topic, and explain the ground rules for the interview in accordance with the previously formulated Focus Group Script. It was reviewed again that participants were under no obligation to participate and that they were free to stop participating at any time. Participants were given a chance to ask any additional questions and then reminded that the video camera and tape recorder would be turned on (as long as they were comfortable with this). The researcher reiterated that no one other than the researcher and supervisor would

have access to the recordings. Once the recording devices were activated, the researcher proceeded to ask the questions outlined in the Focus Group Script, occasionally probing for more information (e.g., “What did you discuss during those interactions?”), redirecting (e.g., “I think this is a really good discussion that I would like to come back to...”), repeating questions, or rewording the question for the participants to understand. Refreshments (water, muffins, cookies, and fruit) were available for participants to enjoy throughout. After the final question, participants were given an opportunity to ask questions or add anything else they wanted to add. The researcher thanked the participants for their participation, reminded them that a copy of their contribution to the interview would be summarized and e-mailed to them for approval, and then escorted both participants back to the parking lot. The interview portion lasted for 64 minutes and the entire session took approximately 90 minutes to complete.

ST Interview 2

The second ST interview was conducted on a separate day in January 2010 and lasted for 90 minutes. The same location was used and the same procedure as ST Interview 1 was followed. An RA however, was not available at this time, so the researcher conducted the session alone. One participant (ST 3) arrived fifteen minutes earlier than the second so the participant was encouraged to enjoy some refreshments and provided with a copy of the informed consent to review until the other participant arrived. ST 3 advised the researcher that she was under time constraints and would most likely have to leave before the interview was complete. Based on this information, the researcher reduced the number of questions asked to the participants and completed the final three questions (of the reduced set) with the remaining participant. ST 3 left the session 27 minutes into the interview. The interview portion lasted for 45 minutes and the entire session took approximately 60 minutes to complete.

Parent Interviews

Parents were recruited in two different locations in southern Ontario. As a result, one interview was held in the same location as the supervisory interviews and the other was conducted in a classroom of the Brock University, Hamilton campus.

Interview 3 (Parent Group 1)

The same procedure as the ST interviews was followed for the two participants who took part in the parent interview on a morning in February for 90 minutes. The Parent Informed Consent Form is available in Appendix H. One parent e-mailed prior to the meeting indicating she would not be able to attend due to sickness. The parent interview lasted for approximately 74 minutes and the entire session took 90 minutes to complete.

Interview 4 (Parent Group 2)

The second parent interview was conducted in a small classroom of the Brock University, Hamilton campus on a morning in February for 90 minutes. The researcher greeted the three participants outside and provided them each with a parking pass. The same format was followed as the previous interviews and the interview lasted for approximately 66 minutes. A security guard interrupted the last portion of the session to remind us he was locking up the building in ten minutes. The researcher was unable to escort the participants out of the building because materials and refreshments needed to be quickly packed away, but the researcher ensured the participants could find their way back to the parking lot and thanked each participant for taking part. Two parents e-mailed the researcher following the session to add additional information that they had forgotten to mention.

Interview 5 (Therapist Focus Group)

Seven therapists attended the focus group discussion at Brock University's Hamilton campus on February 8, 2010 from 6:30pm to 8:00pm. The Therapist Informed Consent Form is available in Appendix I. The session was conducted in a classroom and participants were seated around a large table facing each other. The video camera was positioned in the far corner of the room to ensure each participant was visible on the recording. The same format was followed as the previous interviews however, due to the large size of the group, the researcher asked participants to consider providing responses that were different than that of other participants in order to avoid repetition and to ensure there was time to address all of the questions. Participants were still encouraged to indicate if they agreed or disagreed with one another and many did so throughout the course of the interview. The interview portion lasted 63 minutes and the entire session lasted 90 minutes. The researcher unintentionally missed two questions during the session and later asked participants to respond to the two questions when they reviewed and returned their transcript to the researcher. Six out of seven therapists responded to these questions in this format.

Transcribing

Following each interview, the researcher transcribed each session verbatim in a Word document. The tape recorder malfunctioned for the first interview so the researcher transcribed interview one, as well as the two following it, from the video files. The researcher used Windows Media Player to play the file which enabled the researcher to easily pause and rewind as necessary. The audio quality of the video recordings was poorer for the interviews conducted on the Hamilton campus because the camera was positioned further away from the participants. As a result, the two remaining interviews were transcribed (verbatim) from a new digital voice recorder that the researcher purchased.

Member Checks

After transcribing each interview, the researcher reviewed each transcript twice before beginning to create individual summaries. For each participant the researcher created a Word document summarizing the answers to each question asked during the interview. This summary, including only what that participant said, was electronically mailed to the participant and the participant was given two weeks to make any changes or clarifications or to accept it as it was. The researcher sent a follow-up e-mail at the end of the two weeks to remind participants of the opportunity to review their contributions to the discussion. Twelve out of 16 participants reviewed their transcripts and replied to the researcher. Two STs made clarifications, one IT asked for something to be removed, one parent asked for clarification about something she said, another parent added additional information to three of the questions, and the remaining seven accepted their transcript as the researcher had summarized it. Any changes that a participant indicated were then altered in the original data. Six ITs also provided responses for the two questions the researcher missed in the initial interview which were added to the therapist transcript. The data from the four participants who did not respond to the researcher were not altered.

Data Storage

All written records and questionnaire forms were stored in a locked filing cabinet that only the researcher could access. At the conclusion of the study (after the results have been analyzed and feedback forms mailed to the participants) these records will be shredded. Paper copies of the focus group transcripts will be shredded and electronic copies permanently deleted.

The videotape was also stored in a locked compartment that only the primary student researcher could access. After the final manuscript is approved by the defense committee and the

feedback forms with the summary of results have been mailed to the participants, the videotapes will be destroyed. This will consist of cutting the recording disc and disposing of it.

Participant Feedback

At the end of the study, participants will be provided with a detailed written explanation of the purpose of the study and a summary of the results obtained. If quotes are included from the focus group session to demonstrate a finding, no participant names will be attached. This feedback will be mailed to each participant within a month of the completion of the study (Appendix J).

Data Management & Analysis

In the attempt to construct a theory of coherence surrounding how parents and therapists collaborate within an IBI setting and how it may be improved, the data from all levels of investigation were reviewed numerous times. To manage the data, each full transcript was printed (with no identifying markers), each participant summary was printed, and the responses of each participant to each question were printed. This enabled the researcher to examine the data on a case by case basis, as well as across groups. Ongoing reading of the transcripts enabled the researcher to identify patterns that were then highlighted with various colored highlighters and compared within groups (e.g., the responses of each participant in the ST group were compared to each ST) and across groups (e.g., the responses for each group were compared to the responses of the other groups). The researcher also created a diagram to illustrate the process of this constant comparative analysis. Figure 1 illustrates the cross-case analysis and Figure 2 provides a sample of the within-case analysis for the ST group. The same process was conducted for the parent and therapist groups as well.

Additionally, the qualitative analysis software called NVivo 8 was used to assist with the organization and management of data. This program enabled the researcher to manage all of the data files within one file and sort the raw data according to patterns into thematic clusters. The researcher reviewed each transcript for the following: 1) similarities and differences within groups and across groups, 2) confirmations and disconfirmations of the literature (to address in the discussion), and 3) indigenous typologies (mostly in the form of quotations by participants to contextualize the experiences of this group). The researcher created various tree nodes to enable the coding of highlighted text into hierarchical categories. For example, a tree node was created to represent the importance of 'Role Definition'. The researcher reviewed each transcript and highlighted responses that corresponded with this theme and assigned the coded responses to the child nodes of 'Role Definition' which included 'Understanding your role', 'Expectations', 'Responsibilities', 'Professional boundaries', and 'Training about role'. This sorting process enabled the researcher to calculate the frequency with which particular responses were similar or different and easily refer back to the original context when necessary.

Results

By using the software and through ongoing reading and highlighting of patterns within the hardcopies of the data, the researcher was able to conduct a constant comparative by question analysis that revealed a number of patterns that were used to describe thematic clusters across and within cases. The researcher was also able to select key phrases that served as strong examples of the key patterns and themes identified in the dataset. The researcher made a deliberate decision to include verbatim quotes in an attempt to preserve the language and authenticity of the informant's voice. This section may therefore require a more focused reading, but is in the service of accurately representing the responses of the participants.

The researcher conducted a constant comparative by question analysis of five questions that were asked in every interview: 1) What opportunities do parents and ITs have to interact, 2) What factors do you think promote collaboration between parents and ITs, 3) What do you think interferes with collaboration between parents and ITs, 4) What might be done to improve parent-therapist collaboration from an a) ST perspective, b) IT perspective, c) parent perspective, and d) agency perspective, and 5) Of all things discussed, what do you think is most important? Responses to additional questions asked during different interviews (e.g., Share a positive experience you had interacting with a parent or IT, What are your expectations of parents?) were reviewed for references to these main questions, were compared in any instances in which more than one group was asked that question, and also analyzed for within-group differences.

The cross-case, by question analysis of all of the interviews revealed five main thematic clusters: 1) Role Definition, 2) Perspective-taking/Empathy, 3) Open Communication, 4) Trust, and 5) Consistency. All of these themes were mentioned in each interview and served as a strong representation of the experiences of the participants and what, collectively, they reported as relevant to parent-therapist collaboration in IBI. Each of these themes was also examined for within-group similarities and differences.

Role Definition

As one's role refers to the prescribed or expected behaviour associated with a particular position (Business Dictionary), any instances in which participants discussed the following: 1) importance of understanding what their own and each other's role is/was, 2) the need for clear expectations, 3) professional and personal boundaries in relation to job description, and 4) training regarding role definition, were included under the thematic cluster 'Role Definition'.

There were a number of similarities and differences across groups, as well as within groups, on the considerations for this theme.

Overall, references to Role Definition were made across all five main questions asked by the researcher. Most references were made by STs and related to the importance of ITs knowing and remaining within their role and parents being aware of both the role of the IT and of the parent. Suggestions for improvement from STs included more training for ITs on what their role consists of and clear communication of expectations from all involved. Therapists and parents focused more on behaviour that was outside the role of the IT (e.g., unprofessional relationships, emotional involvement) and the barriers to collaboration due to program policy and lack of training. Suggestions for improvement included training on how to interact with parents, clear guidelines on what constitutes a professional relationship, and changes to policies that restrict outside contact between parents and therapists.

In reference to the importance of understanding one's role, the cross-case analysis revealed discrepancies between the STs compared to parents and therapists. STs repeatedly reported how important it is for ITs to know what their role is, to stay within that role, and that most interaction with parents is designed to be at the ST level. Parents and therapists both agreed that ITs are expected to follow directions from their ST, but point out that they are in more frequent contact with each other than with their STs and that the IT role is restricted by too many rules (e.g., no outside relationships with parents/families, communication with parents limited to a discussion of the child's demeanor).

Responses related to how parents and therapists interact were very informative regarding how the description of one's role differed from how that role is enacted in practice. STs shared experiences of "ITs [who] at times can step out beyond their role and in fact like where they're

trying to do ST by giving feedback about the programs and they shouldn't because that's just not their job description" (ST 4, ST Interview 2, p. 5) and parents who "...tell the therapists what they should be doing and sometimes therapists start to do that, and 'Wait a minute, what are you doing? This isn't a program!' – the ST and the parent have to be setting the goals, they can't be telling the therapist what to do" (ST 1, ST Interview 1, p. 10). Therapists recounted similar experiences. Therapist 5 divulged that "Well half the things that I do, I didn't know if I could do them, I did them anyway. Til I'm told I can't do them, I'm going to do them. And I don't ask questions" (Therapist Interview, p. 16) and Therapist 3 shared that she felt discouraged to build a rapport with parents through small talk despite thinking "...it's so important, and I know I've gotten response from parents that they know kind of who you are because you're dealing with our kids for six hours a day" (Therapist Interview, p. 11).

Parents presented the most extreme variations from the role of the IT described by STs. Parents expressed a desire to discuss personal things with therapists and Parent 1 illustrated this by saying "I want them to be able to tell me what's going on, what their feelings are...and maybe that crosses the line" (Parent Interview 1, p. 8). This preoccupation with "crossing the line" or "overstepping boundaries" was similar across all groups. STs pointed out that it is "sometimes difficult to keep the professional lines" (ST 1, ST Interview 1, p. 3), but that training around what one's role is and what is appropriate, is a way to prevent the crossing of boundaries.

Therapists agreed that there were professional boundaries they were advised to stay within, but were unable to articulate what constituted a professional relationship and several ITs admitted that the guidelines were unclear and that "...not knowing what's right, what's not right, if you're going to get in trouble, if you're not – what you're supposed to do" (Therapist 1, Therapist Interview, p. 21) was one of the most important distinctions that needed to be made.

Parents also had difficulty articulating what was appropriate and Parent 5 insisted that when it came to restricting contact between parents and therapists after IBI services have ended for their child, when relationships have already been established during the time that services took place, the lines get blurred and

...that's the problem...the fine line between being professional and being personal – it's a fine line and you feel like you're walking on egg shells all the time and I don't think it's fair. Our kids are the ones that are suffering and families are the ones that are suffering.
(Parent 5, Parent Interview 2, p. 4)

Within-case differences about the understanding of the role of the IT were apparent in the comments parents made about ITs being responsible for teaching parents how to deliver programs. Parents in the second interview indicated that there were expectations that the ITs train the parent because, as Parent 3 explained, "...We don't know what you know so it's up to you to teach us. That's what I expect" (Parent Interview 2, p. 14). Parents in the first interview did not express similar expectations.

Within group differences for the IT focus group were expressed as variation in how STs choose to manage interactions between parents and therapists. Therapist 1 in the IT Interview described interaction with parents in her employment experience as nonexistent: "I really didn't interact much with parents at all...My ST was the one that made it very clear that she was the one to discuss things with parents, not the ITs" (Therapist 1, IT Interview, p. 3). Therapist 2, 3, and 5 disagreed with this explanation and recounted experiences with an ST who was supportive of interaction between parents and ITs and Therapist 3 pointed out (in reference to interacting with parents) that

...if I hadn't of had that ST who was really encouraging and really fostered those relationships and said you know, of course you can talk to them, of course you can do this...I don't think I would be comfortable with all the relationships with all the different dynamics that parents bring in. I don't know if I would have been apt to encourage those relationships because it would have been like I don't know if I can talk about that, I don't know if I can ask them how their day was, I don't know if I can...(Therapist 3, IT Interview, p. 16)

References to clearly defining each role and "being pretty specific about what the expectations are" (ST 2, ST Interview 1, p. 3) were mentioned by the STs as strategies to maintain a good working relationship between parents and ITs. ST 4 recommends being clear from the beginning of the relationship and speaks of the necessity of explaining to parents why certain decisions are made (e.g., to share information about how the child seemed during session). She has found putting in writing "...brief what the expectations should be from the IT and from the parents in regard to the IT and then likewise the ST and of course the Clinical Director...so they know exactly who to go through for what" (ST Interview 2, p. 6). She also pointed out that she does not think this will be enough and that frequent reminders to parents and ITs are likely necessary (p. 6-7).

Perspective-taking/Empathy

Another prevalent theme was the importance of therapists being able to empathize or take the perspective of parents and vice versa. Patterns that formed this theme included having an understanding of the circumstances parents live in, acknowledgement of the stress parents may be experiencing, recognition that parents know their children best, understanding of the pressure

placed on therapists, and acknowledgement that therapists know their clients well and have expertise to share.

This theme was also mentioned across all five questions asked to each group. STs discussed perspective as “...a tough thing for a lot people” (ST 2, ST Interview 1, p. 11), but as important for both parents and therapists. Conflict between parents and therapists was often explained by STs in terms of having different ideas about how to help the child learn and that “...if the therapist can see things the parent’s not doing, it’s just a lack of understanding how difficult it is from the parents side, but it’s not – it’s all because they want the child to do well and to progress – to develop as much as they can” (ST 1, ST Interview 1, p. 14).

Therapists mentioned, in response to how to improve parent-therapist collaboration, that “I think that if we did practice in training then you would gain that sort of empathy that maybe is feared that ITs won’t have, that they won’t be sensitive or they will say the wrong thing” (Therapist 1, Therapist Interview, p. 20). Parents spoke highly of ITs who were understanding (e.g., “feeling comfortable with her coming and the house being messy or there being dishes in the sink” Parent 2, Parent Interview 1, p. 21), “who gets the feeling of how parents feel” (Parent 5, Parent Interview 2, p. 14), and who “...understand that every little thing that they do is a blessing” (Parent 5, Parent Interview 2, p. 9). Parents also mentioned ITs having empathy for parents (Parent 1, Parent Interview 1, p. 25) as one of the most important things discussed in the interview that day.

Across-case similarities revealed that all groups acknowledge that parents are under a great deal of stress and that it is important to take this into consideration. Parents were especially concerned about the need for ITs to understand what it is like to live with a child with autism and deal with their child’s behaviours on an ongoing basis. Several expressed the desire to share their

feelings with ITs and be able to explain to them what is going on in their life. STs and ITs acknowledged that parents like to do this, but did not indicate that this was a possibility within the role of the IT.

Each group also mentioned that IBI can be intrusive to the family. ST 3, for example, stated “I’m sorry but, especially if it’s home, home-based, umm, it’s a very intrusive thing to have staff, ITs or different professionals...entering their home” (ST Interview 2, p. 8) and parents expressed similar sentiments: Parent 2 said, “Like home is home. This is where we cuddle and read together and, you know, that kind of thing” (Parent Interview 1, p. 1). All three groups also mentioned that training or practice (e.g., role-play scenarios) in perspective-taking would be helpful for ITs to help teach them how to respond to parents and how to be more understanding and aware of what it is like to raise a child with autism.

Differences revealed in the cross-case analysis were noticeable between STs and parents in relation to how understanding parents were of the IT perspective. All four STs mentioned how parents likely do not consider how difficult it is for ITs to come into their homes, how it feels to be monitored by the parents, or how hard it is to deal with a child with a lot of problem behaviours. Four parents however, mentioned that ITs have a difficult role and recognize that they are often undervalued for the work that they do which is indicative of some amount of understanding for the perspective of ITs.

Differences between STs and ITs were also noticeable in relation to how capable STs believed ITs were of understanding the parent perspective. ST 1, for example, relayed the tendency for therapists to focus on the behavioural perspective and subsequently lack understanding of how difficult it is for parents to implement such procedures with consistency.

She highlights the discrepancy between how easy the techniques are for therapists to implement in relation to the parent by saying,

...they're not living with that child 24 hours a day – especially young therapists that are not parents and haven't had to deal with that...I think sometimes those naïve therapists it umm, have to make sure that they do get understanding of how difficult it can be...and try and get them to have an understanding, show some empathy – rather than just saying – being stuck on that behavioural they have to do this all the time without looking at what the barriers to those things may be (ST Interview 2, p. 8).

Therapists agreed that there was a tendency for STs and parents to assume they do not understand the parent perspective or will be “insensitive” (Therapist 1, Therapist Interview, p.20) to it, but several ITs made comments that acknowledged the stress parents are under and the need for parents to have that additional support (Therapist 4, Therapist Interview, p. 10). The within-case analysis of the therapist group however, also indicated that ITs have high expectations for parents that may not reflect a true sensitivity to the situation of parents and the understanding that they report that they require.

Within-case disagreement also occurred between Parent 4 and Parent 5, the latter which was not convinced therapists could really understand what it is like to be a parent living with a child with autism every day, and the former satisfied that “the ones that are like that, that really umm, connect with your child and you get closer with...get it as much as they can” (Parent Interview 2, p. 15). A lengthy conversation pursued about the inability to learn empathy from a textbook and how hard it is for ITs to grasp the emotional side of seeing one's child suffer (Parent 5, Parent Interview 2, p. 15) while Parent 4 conceded that ITs “definitely don't live it 24-7, but there are, like I said for me...those that seem to be better...[who] get it more” (Parent

Interview 2, p. 15).

Open Communication

Open communication was discussed within all groups as an essential type of interaction between parents and ITs that involved communication between all team members, as well as the need to share important information with one another. Parents mentioned communication as the most important component of parent-therapist interaction and Therapist 4 said “If you don’t have it, then I mean what’s the likelihood of success for that child in the future, you know?” (Therapist 4, IT Interview, p. 13). STs also acknowledged the importance of communication between parents and therapists, but were more focused on the communication of information that was relevant to the session, such as the child’s demeanor, than other information. Each group also mentioned the importance for open communication between ITs and STs. ITs were dubbed “...conduits for communication” (ST 2, ST Interview 1, p. 9) between parents and STs and parents described often relying on ITs to relay their input to STs (Parent 3, Parent Interview 2, p. 16). Additional across-case similarities between ITs and STs, but not mentioned by parents, were that some parents are more difficult to communicate with than others and some parents do not always share important information with their team members.

Parents agreed that open communication between all team members is necessary, but differed from the STs in that the information they thought was important, or wanted, to communicate with therapists (e.g., personal information, how they were feeling, and the opportunity for small talk) that was beyond the role the ST outlined for ITs. The within case analysis of the therapist interview found that ITs discussed a similar desire to communicate with parents about other information. Therapist 1, for example, pointed out a desire for parents to communicate limitations surrounding why they may not be able to do something that was asked

of them (Therapist Interview, p. 2) and Therapist 3 felt parents should share changes in family dynamics that might be affecting the child (p. 8), whereas STs felt that information other than directly related to that day's session should be directed to them.

Within group differences regarding communication were relegated to the therapist group and involved small discrepancies between how comfortable ITs felt approaching STs with suggestions. One therapist expressed feeling intimidated about communicating to her ST a desire to interact more with parents (p. 16) but several others quickly voiced that that experience would be dependent on one's ST and that they had only positive experiences with their STs and reported them to be very encouraging about parent-therapist interaction (p. 16).

Trust

"Trust" referred to discussion about trust as a necessary component in a parent-therapist relationship and how that ability to rely on someone is developed over time. The within- and across-case analysis uncovered very similar views about trust and the importance of establishing a trusting relationship. All groups mentioned that their children, or the children they are/were working with, are vulnerable and that it would be difficult to "...trust just anyone with them" (Parent 4, Parent Interview 2, p. 6). Parents expressed the need to know about the person who works with their child, especially because they are coming into their homes, and therapists agreed with this sentiment indicating that "they [parents] need to know certain aspects about you and be able to small talk with you" (Therapist 3, Therapist Interview, p. 11).

Parents and STs also mentioned the requirement of being able to trust that the IT knows what she is doing and that she is doing what she is supposed to be doing. Parent 3 mentioned it was important "...to be able to trust not only like the care of our child, the safety of our children, but also umm, trust that they umm, won't waste the time – that they will be productive" (Parent

1, Parent Interview 1, p. 18). STs shared experiences about parents expressing concern that a therapist is not doing his or her job when the parents only hear silence from the therapy room (ST 1, Interview 1, p. 3). The ST pointed out that this is probably more a lack of understanding that the therapist could be physically prompting or doing a variety of different things that may not require verbalizations.

Overall the general sentiment about trust was that:

There needs to be a trust. There needs to be some kind of rapport so that the parents umm, have some confidence in the skills of the therapist because they are giving their child, their vulnerable child, over for a couple hours a day or however long, umm, to this person who is a stranger initially. You do need to set up some, some trust and relationship there. (ST 1, Interview 1, p. 4)

In the results of the within-case analysis however, three therapists did mention that after that initial trust is established, parents should no longer feel the need to question everything the IT does (Therapist 2, Therapist Interview, p. 9) and as a result, respect that the IT is doing his or her best for their child (Therapist 3, Therapist Interview, p. 9). Parent expectations of how to gain that level of trust – by really getting to know the therapist who is working with their child – is also contrary to the roles outlined for the ITs, but parents repeatedly raise the need to do so. Parent 1 even shared an unfortunate incidence of physical abuse that her child experienced as rationale for the importance of knowing who is working with your child and being able to trust that individual (Parent Interview 1, p. 10).

Consistency

The theme of ‘Consistency’ included references made by participants about the importance of maintaining a regular team who works with a family, sending a consistent

message to parents, and the difficulties associated with trying to maintain consistency. The across case analysis of Consistency revealed mostly similarities. All groups mentioned variations across teams and turnover rates as a barrier to parent-therapist collaboration. ST 3, for example, mentioned that, "...it's hard in terms of turn over umm, so if you want the parents to have a positive rapport with the ITs that are on their child's team, ummm, maintaining those ITs within that team are important" (ST 3, ST Interview 2, p. 4). Similarly Parent 3 explains,

A little bit too much moving around, yes, and I don't think that's fair to anybody involved because you're going through that whole process again. Let's get to know them. And when your time's limited in IBI...we can't be doing these things to families, to therapists, to everybody. (Parent 3, Parent Interview 2, p. 11)

Therapists discussed consistency as an expectation parents would have and STs confirmed this expectation by highlighting that "we've got a number of at least three therapists working with the same child so you need consistency umm, and you want to give the parent a clear message and not have people say different things" (ST 1, ST Interview 1, p. 5). Parents concurred as well pointing out that without consistency things would not work because the same issue needed to be handled in a similar way and parents and ITs "...need to be on the same page" (Parent 1, Parent Interview 1, p. 18).

Differences regarding the topic of consistency were also detected in the cross-case analysis. Parents discussed the need for themselves to be more consistent in the way in which they implemented suggestions from ITs and STs about managing their child's behaviours. Therapists addressed this topic in terms of respect for the expertise they have to offer parents rather than an opportunity for consistency within the home setting. Finally, STs acknowledged

that consistency was an important factor but that it is often difficult for ITs (especially young ITs who do not have children) to understand that consistency is a hard goal for parents to maintain.

Parents also discussed the difficulty ITs have maintaining consistency when they are working with so many different clients. Parent 3, for example, voiced that it was unreasonable to assume therapists can be “put from here to there to here to there to here to there working with all these different kids...and be able to...actually get to know programs, know what’s going on, know the child” (Parent 3, Parent Interview 2, p. 8) all the while being “...critiqued on how umm...consistent they are and that they’re doing what they’re supposed to be doing” (Parent 3, Parent Interview 2, p. 8). Neither STs nor therapists expressed concern with working with a variety of different clients.

The within-case analysis of the theme of consistency did not yield differences in how participants viewed consistency for the ST and therapist groups. Parents however, differed slightly on the practicality of being consistent in the home setting. Parent 2 (Parent Interview 1, p. 11) mentioned therapists probably expect consistency in the follow-through of their suggestions at home, but relayed an experience of not being consistent in responding to her child’s self-stimulatory behaviour because she would often give him items to self-stimulate with in order to keep him occupied. Parent 1 justified this behaviour by commenting that if it is working for you, then “...stimming in front of the television for half an hour so that I can get dinner on the table that’s ok you know. We’re only human” (Parent 1, Parent Interview 1, p. 12). Parent 2 was very adamant that it was in her best interest to try to be more consistent in managing this behaviour and ended by expressing that to have that consistency it is “...important to be able to work with the therapist even though you really don’t want to or you don’t have the time or stuff really to be able to alter some things too” (Parent 1, Parent Interview 1, p. 12).

These five main broad themes highlight the main differences and similarities associated with the different roles and lived experiences of members of this hierarchically structured system. ST interviews were included for an overarching view of parent-therapist relationships and because STs are responsible for coordinating interactions with parents in an IBI setting, while parents and therapists were consulted because of a lack of attention in the research on hearing their perspectives. As a result, the cross-case analysis between parents and therapists, as well as the within-case analyses of these groups, were of particular importance in this study. From this analysis, some additional patterns were recognized that highlight some of the concerns for parents and therapists in IBI settings as well as represent the unique experiences of this particular group of participants.

Additional patterns or concepts that were repeated across both ITs and parents were topics related to Respect, Undervaluing of ITs, Language, and Outside Relationships. Both groups (cross-case analysis) presented similar thoughts about having respect for each other. Parents highlighted the need to respect the suggestions ITs provide to parents (Parent 2, Parent Interview 1, p. 11), as well as the importance of the job ITs do with their children (Parent 1, Parent Interview 1, p. 25). Therapists also talked about mutual respect in terms of parents respecting ITs as professionals (Therapist 2, Therapist Interview, p. 9), reciprocating respect to parents who participate in sessions ITs have prepared for (Therapist 3, Therapist Interview, p. 9), and respecting that parents should have the last say because it is their child (Therapist 6, Therapist Interview, p. 10). Parents also referred to respect when discussing how well they know their child (Parent 5, Parent Interview 2, p. 16) and the value of the input they have to offer ITs (Parent 3, Parent Interview 2, p. 18).

Parents and ITs similarly discussed the tendency for ITs to be undervalued. Parent 4 described ITs as "...the low man on the totem pole" (Parent Interview 2, p. 7) and therapists referred to themselves as "just the lemming" (Therapist 3, Therapist Interview, p. 16) and "just the donkeys" (Therapist 7, Therapist Interview, p. 18). Furthermore, Therapist 1 spoke of how

...when you're just treated as a staff, front line staff who needs to do this and don't step out of that and just do what you're supposed to do and don't say anything wrong...I think it just kind of deflates therapists a bit. It's like well, this is all I am. (Therapist Interview, p. 13)

Parents also supported this theme by agreeing with each other that the good therapists, whose "...hearts are in it" (Parent 5, Parent Interview 2, p. 15) are not valued enough.

Therapists differed from parents on this topic in that they expressed frustration, especially when sharing disappointing experiences they have had interacting with parents, about the lack of acknowledgment from parents of the amount of time they spend with their children (and what they learn about them during this time) (Therapist 1, p. 5 & Therapist 3, p. 7 & 8) and also the amount of time spent preparing materials and resources that are underappreciated or not used (Therapist 3, Therapist Interview, p. 6).

Both parents and ITs also made references to the behavioural language that is used in IBI settings. Parents pointed out that it is a different language than their own and explained that they need help to understand it. Parent 3 recalled taking it upon herself to learn much of the terminology, asked a lot of questions, and shared this information with her friends. Parent 5 however, points out that not all parents are capable of doing this and it should be up to ITs to explain things in a way that is understandable to parents. Therapist 6 continually reminded the

group that as ITs they do use a different language that is not necessarily parent-friendly and Therapist 2 and 7 agreed that steps needed to be taken to explain things thoroughly to parents.

Distress over the policy that parents and ITs are not permitted to contact one another until two years after IBI services have ended was apparent in all of the parents. The personal choice to have outside relationships, that did not include providing IBI, was a major concern for parents. Parents felt it should be an ITs decision if they wanted to provide respite to a family they also provide IBI for and that, oftentimes, outside relationships were necessary to “build a connection with their child” or promote socialization that parents did not feel was met in restricted IBI settings. Therapists, especially Therapist 3, expressed concern about the restrictions surrounding participating in community events in support of autism. Therapists explained that policy dictates that they should not attend due to the possibility of interacting with parents in a non-professional setting, but expressed experiences of discouragement. Therapist 3, for example, explained that “I’m in this field because I’m really supportive of this so you think we’d be more encouraged to participate in that community and we’re not. At all.” (Therapist Interview, p. 12). Parents also expressed interest in having therapists participate in fundraising or social events and agreed that too many restrictions were being placed on therapists.

Patterns within the parent interviews addressed Privacy, Emotion, Fear of Speaking up, Bending the Rules, Being Treated as an Equal, and Textbook to Real Life. In reference to barriers to collaboration, all parents discussed a fear of speaking up, not being treated as an equal, and the difference between learning about autism in a textbook and what it is like in reality as problems within the IBI setting. Respecting parent privacy by not sharing information about their child with other therapists, bending the rules in reference to allowing contact with ITs

outside of IBI or making exceptions about doctor's notes, and enabling parents to share the emotional side of things with ITs, were all requests parents wanted to be considered.

And finally, additional patterns within the therapist interview were related to Training. In response to the question about training and support therapists are provided with on how to interact with parents, therapists were quick to respond that there is no training. Therapists expressed concern that they are also lacking in training on how to conduct generalization sessions with parents and voiced a desire for regional training to address this gap. Additionally therapists felt being provided with scripts to read to parents about particular issues was a contrived way to interact with parents. Therapists suggested a training module be offered to them that includes role-playing parent-therapist interactions so that the practice will prepare them for how to communicate with parents: "Like if you're practicing and you're given really tough scenarios and you have to think on the spot of how you're going to say it, and the you get feedback from everyone else, I think it would just ease the nerves" (Therapist 1, Therapist Interview, p. 20).

Discussion

Due to the lack of qualitative research in IBI settings that examines both the parent and therapist perspective, the literature that was the foundation for this study was drawn from related fields such as mental health settings (Andonian, 2008), occupational therapy (Hannah & Rodger, 2002; Thompson, 1998), and both quantitative (Able-Boone et al., 1992; Raghavendra et al., 2007; Solish & Perry, 2008) and qualitative studies (Benson, Karlof, & Siperstein, 2008; Bjorck-Akesson & Granlund, 1995) examining parent and professionals, but not typically front-line workers, in early intervention settings. From this literature, a wide variety of potential

contributing factors that may or may not have been relevant to parent and therapist perspectives in an IBI setting were identified.

In comparing the responses provided by the participants in this study to such possibilities, a number of parallels were found between this related literature and the experiences of parents and therapists in IBI. The benefits of collaboration suggested in the literature, such as higher levels of parental satisfaction and improved parenting strategies (Brookman-Frazee, Stahmer, Baker-Ericzen, & Tsai, 2006; Spann, Kohler, & Soenksen, 2003), were confirmed by the positive experiences shared by parents and therapists. Examples provided by parents that focused on how much they had learned from therapists about their child and about how to teach their child and were described as experiences that were “invaluable” (Parent 5, Parent Interview 2, p. 8). Therapists also discussed positive parent-therapist interactions in terms of “...giving the parents like the success...taking it to their house and showing them what we do...and then they get it and they’re like ‘Awesome, finally!’” (Therapist 5, Therapist Interview, p. 5) and how “...they get so much more out of it and so does their kids” (Therapist 3, Therapist Interview, p. 3) when an open and communicative relationship exists between parents and therapists.

Parental involvement was also discussed in a similar fashion to that of previous studies examining this component of early intervention (Case, 2001; Renty & Roeyers, 2005; Solish & Perry, 2008). Parent involvement was described in relation to a spectrum with uninvolved parents on one end, over-involved on the other and “a whole range in between” (ST 1, ST Interview 1, p. 10). Parents in this study also shared experiences about their level of involvement that confirmed the existence of such a range. One parent shared that “...I was not involved. I wanted to drop them off at the center. I didn’t want them in my home either...my involvement was limited” (Parent 2, Parent Interview 1, p. 1). Others however, were very involved by virtue

of expressing their interest in taking as much as they could from the experience and by describing IBI as "...what you make it" (Parent 3, Parent Interview 2, p. 6).

What the most beneficial amount of parent involvement is and how this is cultivated however, remains to be seen. Solish and Perry (2008) describe factors such as self-efficacy, belief in IBI, knowledge of autism and IBI, perception of child progress, and stress as predictive of parent involvement and some of these factors were mentioned by the STs, but it was very clear that these qualities were determined from a service-provider perspective and were not necessarily representative of parent and therapist needs. Parents repeatedly mentioned the need to refrain from treating each child and their family as a 'textbook case' (Parent 1, Parent Interview 1, p. 17, 23, & 25; Parent 5, Parent Interview 2, p.15) and therapists agreed that taking the time to figure out what parents really want from this experience has guided how they interact with that family (Therapist 4, Therapist Interview, p. 3).

A prominent theme of this study was the importance of clear role definition. Several therapists expressed confusion over the scope of their role. In reference to a discussion about providing research findings to parents and who should address concerns about non-evidence-based practices, IT 2 expressed feeling comfortable doing so while IT 7 explained that she felt that fell under the role of the ST. The conversation ended with IT 2 exclaiming "So now my understanding of the role's kinda blurred!" (Therapist Interview, p. 15). Lack of understanding around the policies for personal-professional relationships with parents just add to the confusion of the IT. IT 6 stated "Uncertainty about how to collaborate effectively while maintaining professionalism" (Member Check Correspondence, March 1, 2010) as a barrier to parent-therapist collaboration and IT 2 also explained that, "...it's all these whispers and 'oh, I heard

you can't do this' and 'I heard that you can't...'” (Therapist Interview, p. 20) which agencies need to address in order to improve interactions between parents and therapists.

Of the challenges to service provision the researcher originally chose to highlight in the literature review, parents and STs confirmed that differences in personality (as mentioned by Thompson, 1998) may inhibit collaboration. When discussing the variety of things ITs explain to parents, Parent 5 insists early in the interview that “...it depends on personality” (Parent Interview 2, p. 2) and refers back to personality when it comes to including other siblings in therapy sessions for generalization (p. 10) and finally she explains “...to me a perfect IT is a match to me. My same personality, that's what I want” (p. 14). Parent 1 mentions problems with Parent 2's comment about therapists who “...don't have the personality to be really social” (Parent 2, Parent Interview 1, p. 8) because she feels you need to have social skills to work with a child with autism and to be able to communicate your feelings. ST 2, in reference to the differences in how ITs handle telling parents who talk quite a lot that they need to do their job (ST Interview 1, p. 3), acknowledges that “you're dealing with personalities” (p. 3). Her comment that followed about using scenarios in training to practice what to do in that situation, however, implies that ‘personality’ may be serving as a scapegoat for a skill deficit or a need for training and support when it comes to ITs knowing how to interact with parents. Bjorck-Akesson and Granlund (1995) discuss how collaborating with families requires other competencies than working directly with the child suggesting it may be helpful to ascertain what these competencies are and develop training modules to address these as necessary.

Administrative policies and routines, as highlighted in the theme of Role Definition and Perspective-taking taking/Empathy, were presented as a prominent barrier to collaboration. Such findings were analogous to the results obtained by Bjorck-Akesson and Granlund (1995) in their

study on family involvement in assessment and intervention. Parents and therapists in the current study, each of whom are directly impacted by these policies, discussed problems with these restrictions whereas STs, who may not be directly impacted by these policies, did not. It is possible that this may reflect a lack of understanding of why these policies are in place. This could potentially be addressed in training or parents may benefit from a support group that allows them to share their similar experiences and voice their frustrations. Therapists may also benefit from an opportunity to share their experiences with one another and support staff on a regular basis.

Differences, which were of interest to note, included disconfirmations of the provider-driven paradigm wherein professionals, or in this case ITs and STs, are traditionally looked upon as the experts (Osher & Osher, 2002). One parent shared an experience of disappointment in which

...they [ITs] were always asking me and umm, I didn't mind telling them things that they enjoyed and stuff like that umm, but when it came to how to deal with it, I didn't know and they were asking me and I'm like well, you're the experts, shouldn't you know that?"
(Parent 2, Parent Interview 1, p. 2)

Similarly, Parent 3 expressed that "...I also find a lot of parents know a lot more than what some of the ITs do" (Parent Interview 2, p. 18). Such responses suggest IBI settings may not represent the traditional provider-driven paradigm, but that a different framework is needed to account for the hierarchical structure of IBI in which the expert (ST) is overseeing the less-expert (IT) service-provider. Also, because many parents are beginning to view IBI, as Parent 5 so aptly stated, "...as an education tool that I could take...because IBI is not going to be there forever and my role as a parent...is to learn as many techniques as I can in order to help [my child] be

successful” (Parent Interview 2, p. 1), it is important to consider how to include the parent who is capable of a more active role. Finally, the implications of the less-qualified experts – who raise the question “...do the ITs know why they are doing some of the things they are doing?” (Therapist 1, Therapist Interview, p. 17) themselves – spending much more time with the client than the decision-makers (e.g., STs, Clinical Supervisors) and how this may influence collaboration, should be examined.

There was little mention of the personal barriers such as lack of knowledge or skill, lack of resources, or family characteristics that may interfere with the formation of collaborative relationships. When presented with the opportunity to reflect on how additional supports affect the ability to collaborate with one another, as well as ways in which one’s own group could try to improve collaboration, parents and therapists mentioned very few personal limitations. Responsibility was instead assigned to the other groups and was often directed at management level. Family or team support was rarely mentioned and was only briefly elaborated on by two parents when the researcher specifically probed for information regarding additional support systems. Some therapists mentioned the benefits of having an ST who was supportive of parent-therapist interactions, but another quickly pointed out that “I betcha that ST fought the system” (Therapist 7, Therapist Interview, p. 16).

It is possible that these topics were not relevant to the experiences of the participants in this study or that the things that they did discuss were more relevant and important than those the researcher chose to focus on in the preliminary stages of the study development. Following the analysis it became apparent that additional areas in the literature needed to be consulted to provide more theoretical context to the experiences shared.

Breadth of Responsibility

Nelson, Summers, and Turnbull (2004) investigated family-professional relationships within a special education setting and specifically identified going beyond a strict interpretation of one's job description in working with families and dual relationships (fostering friendships, mutual support, or other roles in addition to a strict parent-professional relationship) as boundary issues. The authors refer to breadth of responsibility as professionals or agencies providing services that are not within a narrow role but may be within a broader scope of professional responsibilities. A downside, reported by Nelson et al (2004), to not clearly identifying what these responsibilities are is that it places the professional at risk of overstepping their professional role or narrowly interpreting their job requirements.

Nelson et al (2004) also pointed out that as the boundaries broaden the need for flexibility and administrative support increases. This is an important point to keep in mind when considering the interest parents and therapists expressed about having contact outside of IBI (e.g., community events, respite services, family dinners). Because parents and therapists reported that such contact does occur and that they would also like management to consider formally permitting such contact, consideration also of what type of supports need to be in place to manage this contact needs to occur.

Nelson et al (2004) also mention that because functional instruction for students with disabilities often requires teachers to work with students in vocational, leisure, or other community settings, questions about boundaries will be raised making it crucial that parents and teachers have a clear understanding of their roles. Parents and ITs, specifically when the IT conducts therapy sessions in the clients' home, may face additional pressure to challenge professional boundaries. Parents reported inviting therapists over during Christmas holidays and on weekend outings as well as a desire to invite therapists to dinner. Such examples demonstrate

the importance of preparing therapists to respond to such requests in a respectful way and of the necessity of reviewing the boundaries with each team member on a regular basis. Finally, while not mentioned in the interviews conducted for this study, it is important to keep in mind that the emotional toll of opening boundaries can lead to increased stress, exhaustion, and burn-out, so the goal needs to be to find a mutually rewarding situation for both parents and therapists (Nelson, Summers, & Turnbull, 2004).

Parent-Professional Relationship Boundaries

As mentioned in the 'Role Definition' theme, a number of references were made by STs about the importance of maintaining professional boundaries between parents and therapists. Parents and therapists also raised issues about what a professional relationship between parents and therapists consists of and how it can be maintained, suggesting it is important to consider the implications of relationship boundaries for current practice and future research endeavors. For the present study however, the researcher did not probe into the justification for maintaining such boundaries. If questions about relationship boundaries had been formulated from the outset there would have been an opportunity during the interviews to probe for more information. The lack of extensive data on this topic however, prevented an analysis of the differences in perspectives. From the experiences shared in the interviews for this study, it was clear that each group acknowledged that these boundaries exist, but why these boundaries are in place or what actions constitute "crossing the line" should be investigated in further detail.

Professional relationship boundaries are elusive and many disciplines, such as social work, have struggled with how to define professional conduct (Davidson, 2005). Rigid professional boundaries, as described by Davidson (2005), can lead to unequal partnerships and staff who follow rigid professional boundaries are often described as lacking authenticity and

sensitivity. Entangled professional boundaries, however, reflects an over-involvement with the client and family to a point where the staff's own emotional, social, or physical needs are being put before the needs of the client (Davidson, 2005). To find a balance between this continuum, one that parents describe in this study as "...bending the rules a little bit" (Parent 1, Parent Interview 1, p. 16), is a process that involves assessing the knowledge-based competencies that enable staff to identify boundary violations, apply critical thinking skills to complex parent-professional relationships, and their ability to use prevention strategies (Davidson, 2005). Considering the findings of this study, though not central to the initial investigation, indicated that there is confusion over what these professional boundaries are and how to maintain them, and that studies in other disciplines have identified a complex skill set required to understand and negotiate such boundaries, it will be important for agencies to address such concerns through discussion and training.

Research Questions

At the outset of the study, recall that the researcher was interested in five overarching questions: 1) How do parents and therapists currently interact within the context of IBI services, 2) What are parent and therapist expectations of each other, 3) What are factors that promote parent-therapist collaboration, 4) What does each group perceive as the barriers to open collaboration, and 5) How might the parent-therapist relationship be improved? A wide variety of answers were provided for these questions, as has been demonstrated by the excerpts shared above. One of the benefits of this study was gaining a deeper understanding of the issues directly relevant to the participants and the contexts within which they live and work. To highlight some of the general issues that may be relevant to IBI settings (without assuming that these results are

generalizable), the researcher will focus on the results with the clearest implications for IBI service-providers and users.

In reference to how parents and therapists currently interact, there were some discrepancies between groups. STs described parent-therapist interaction within the confines of the expected role of the IT, but admitted that this role is not always adhered to. The expectation was that ITs greet parents upon arrival, ask how the child's day has been going, and at the end, briefly summarize how the child was during the session in a positive way. ITs were also expected to advise parents to consult with the STs for additional information. Parents heavily stressed the need to discuss more with ITs, such as how the parents are feeling, successes and challenges they have experienced with their child, how much they love their child or children, and what it is like to be a parent of a child with autism. Therapists discussed the need to engage in small talk with parents to build a rapport but overall the experiences shared did not reflect what the STs would describe as 'stepping beyond their role'. Instances where that was a possibility (e.g., discussing non-evidence based practices) were followed by a discussion of uncertainty about whose role that falls under. Both parents and therapists expressed interest in being able to have outside relationships with parents (e.g., provide respite services, attend community events for autism) and some shared stories of doing so without permission, but there was collective acknowledgement that this was against policy.

Parent and therapist expectations of each other were generally high suggesting a need for management or senior level staff to routinely review the role descriptions with parents and staff and consider a discussion of reasonable expectations to uphold. Some expectations that the parents discussed that seemed to fall out of the realm of the IT role or were subjective qualities were, "...taking initiative to figure things out" (Parent 2, Parent Interview 1, p. 11), "love your

job” (Parent 1, Parent Interview 1, p. 23), “being there for the right reasons” (Parent 1, Parent Interview 1, p. 25), and “For our kids you need to have that connection – you need to. If you put them in with an IT that’s not jiving with them, then they’re not going to learn” (Parent 5, Parent Interview 2, p. 10). Similarly, therapists also had expectations of parents that may not be reasonable for all parents to attain (for a variety of reasons) such as “...be involved. To take criticism, be willing to learn, to be able to be willing to implement things at home, to be willing to come in and spend the time and really get to know their child and what we do with them” (Therapist 3, Therapist Interview, p. 8) and “...to definitely take what we show them and use it for the rest of the hours that we’re not with them” (Therapist 5, Therapist Interview, p. 8).

Factors that promoted collaboration were, as discussed by the STs, knowing and staying within one’s role, having similar goals, the knowledge and experience of the IT, and having empathy on both sides - the IT having empathy for the parent and the parent having empathy for the IT. Therapists discussed parent involvement, having a rapport with the parent, parents being accepting of feedback, a supportive ST, mutual respect, and trust as factors that promoted collaboration. Some of the factors discussed by parents included open communication, being there for the right reasons, being treated as an equal, and empathy for the parent, among others. The main overlap of factors presented that promote collaboration were knowing one’s role, empathy, trust, communication, and consistency which can be noted as the five overarching themes derived from all responses.

Numerous barriers to collaboration were discussed. Despite the obvious barriers that are opposite to those factors that were suggested to promote collaboration, barriers that were repeatedly highlighted by STs were unclear expectations, stepping beyond one’s role, lack of perspective, the “bottom line” of IBI and pressures associated with trying to reach a certain

behavioural criterion, and personality differences. Therapists focused on rules and policies, uncertainty about what constitutes a professional relationship, lack of parent involvement, and lack of training as the largest barriers to collaboration. Parents unanimously reported rules, policies, and “red tape” as the biggest barrier, followed by restricted settings, lack of alternative services to choose from (because IBI may not have been right for their children but they felt they had no other choice), fear of speaking up, high therapist turnover, and failure to include parents in team meetings about their child.

Ideas for ways to improve parent-therapist collaboration were almost exclusively discussed in terms of changes that need to be made from an agency or systems perspective. Parents and therapists both reported that “ITs’ hands are tied” (Parent 3, Parent Interview 2, p. 20) and most parents felt as if there was nothing they could do either. STs discussed a need for additional training that includes role definition and perspective-taking for therapists. One ST suggested there may be a need to revisit policies if they do not seem to be working, but did not imply that this was the present case. Overall, STs believed parent-therapist relationships were good as is and that “...the things that extend out in the extremes...they’re not the norm” (ST 2, ST Interview 2, p. 14).

Both parents and therapists suggested including parents in team meetings as a good way to improve collaboration. Parents suggested agencies need to be more flexible when it comes to policies and procedures, especially regarding the policy for no contact within two years after the end of IBI services. Parents suggested having the ITs and agency sign an agreement that if ITs chose to provide respite, for example, outside of IBI that they will not conduct therapy during that time and that they are responsible for what happens during that time, not the agency. Otherwise parents were not sure how to accommodate their requests without bending or breaking

the rules. Therapists discussed all of their suggestions for improvement in terms of training. They recommended their initial training include a clear explanation of each team member's role, role-play scenarios to practice how to interact with parents, specific training on how to conduct generalization sessions with parents, and written guidelines to refer to. They did not have suggestions for how to address their concerns with too many rules and restrictions.

Overall the participants directly addressed each of the research questions suggesting the questions asked in the interviews were sufficiently designed to investigate this topic. The wide range of topics raised by the different groups and different perspectives between– and even within the groups – suggest that context is an extremely important factor to take into consideration. Parent 5 accurately sums up this conclusion by stating “Well, treatment isn’t a one size fits all approach” (Parent Interview 2, p. 16). It is thus important for service providers to consult their staff and clients on what is important and relevant to their current circumstances and acknowledge that these needs may change over time. The researcher believes that this study is a start to encouraging this type of dialogue among team members in IBI settings and, although there are challenges to arranging such discussions, would recommend trying to provide such forums for discussion in order to best meet the needs of clients.

Challenges

There were a number of challenges associated with conducting this study. Recruiting therapists was a protracted process because the researcher was initially led to believe it would be possible to recruit potential participants from a regional program. Three months later however, the researcher was informed by the agency that had been approached that, due to a sensitive clinical engagement process they have been in between families and service providers, conducting research in this area at this time might, unintentionally, affect the services their

agency provides. Because the researcher was originally interested in interviewing participants from regional and private settings to gather as much information as possible about how parents and therapists collaborate, as well as to share the strengths of each approach to collaboration and outline ways to improve it, the political undertones associated with a comparison of DFO and DSO services may have overpowered the attempt to understand this aspect of IBI.

The same hesitations were also expressed by the participants who took part in the study. An ST from a private program and one from a regional program attended the same interview, and while both independently assured the researcher they were comfortable discussing this topic together, it was clear that there are underlying tensions surrounding what type of program parents choose. Parents were also very concerned that they were not participating in a session with individuals who might know someone from the agency their child received services. One parent contacted the researcher by e-mail at 1:30am the night before the arranged session to express her concerns on this matter. Because the researcher did not know the parents or the therapists, there was no way to be absolutely sure that the therapists who had agreed to participate did not know anyone from the agency the parents received services from. As a result, the researcher contacted the therapists and cancelled the joint session. The researcher was therefore, not able to conduct the final level of interviews that was designed to provide parents and therapists a chance to interact with one another and brainstorm strategies for how to improve collaboration between parents and therapists.

Due to the various demands on the time of parents and staff participants, scheduling interview times was a difficult task. For example, the majority of parents were only available on certain mornings of the week and had to schedule around work, IBI, school, child-care, and additional commitments. Sickness and time constraints which limited the amount of time

participants could stay were also challenges the researcher needed to work around. As a result, some questions were not asked to all participants and the researcher was not able to conduct the final level of interviews (i.e., Combined Parents and Therapists).

An additional challenge was associated with the researcher's lack of interviewing skills. A focus group script was carefully designed and practiced before each session so that the researcher was comfortable and familiar with the process for each session, but in hindsight the researcher became aware of probes that could have been inserted and topics that could have been elaborated upon. The researcher also found it difficult to redirect participants at times when they were discussing topics not directly related to the question asked. With each opportunity to moderate a session, the researcher became more confident and proficient, but this skill has yet to be honed.

Strengths & Limitations

This study serves as a strong starting point for attempting to understand the dynamics among parents, therapists, and senior level staff in IBI settings. Because therapist perspectives have often been overlooked in the literature and, to the researcher's knowledge, a comparison has not been conducted among these three levels of stakeholders in this setting, it is a step in the right direction toward listening to the voices of those directly impacted by the structure and management of the same system. By conducting a cross-case comparison and within-case comparison of parent, therapist, and senior level staff perspectives on how parents and therapists interact, factors that promote and impede collaboration, and ways to improve such collaboration, the researcher has gained important insight into what each group and participant identifies as important to them.

Additional strengths of the study include the variety of participants consulted in the interviews. In addition to three different levels of service-providers and users, the sample also represented voices of parents from two different locations and three different agencies, parents who have two or more children with autism or other special needs, parents who work and parents who do not, parents who were eager to be involved in the process of IBI and parents who were not, parents of children currently in IBI and parents of children previously discharged, and parents of children who have received private and regional IBI services. The therapist perspective was comprised of previously employed ITs and current ITs from four different locations (three within province and one from outside Ontario), and therapists who worked in regional and private IBI settings and the ST perspective represented three different agencies, one regional and three private. This diverse sample enabled the researcher to gather information from various vantage points and increases the likelihood that the information compiled will be relevant to a wide range of service-providers and clients.

Sampling from senior level staff, front-line staff, and parents of clients (multiple sources of evidence) was used to triangulate the data for this study. This increases the accuracy of the study because the information is drawn from a number of different individuals who have had experiences in an IBI setting. Additionally, member checks, in which each participant was sent a summary of the comments she made in the discussion to add, change, or comment on, served to increase the credibility of the data by providing participants the opportunity to review and confirm each response. Seventy-five percent of the participants took this opportunity and informed the researcher of information to add, remove, or retain. A number of participants also expressed that they appreciated this step in the data collection process and that it was a good way to ensure participant experiences were portrayed correctly. Both triangulation and member-

checking have been identified as methods of verification analogous to establishing internal validity in quantitative research (Anfara, Brown, & Mangione, 2002) and are recognized as important strategies for validating qualitative research.

Unfortunately time constraints and limited access to a potential pool of participants (e.g., agencies employing ITs) decreased the sample available from which to recruit participants. As a result, random sampling of participants could not be employed and a purposeful sample was obtained instead. Parents who knew each other and STs and ITs who worked for the same agency participated in the study and all participants had valuable information to provide and unique experiences to share. It is possible however, that information was left unsaid because of these previously established relationships. Parents in the second parent interview, for example, indicated that they have previously discussed this topic (and others related to it) within their group of friends. It is therefore possible these parents may not have raised topics they had recently discussed or conversely, may have focused more prominently on most recently discussed issues.

Another potential limitation is the search and selection bias of the researcher. The researcher's interest in this subject was based on reflection on previous experience as an IT in two different provinces in which parent-therapist interaction was qualitatively different in both settings. Such a background was a strength in terms of providing the researcher with a general understanding of the structure of IBI and the various relationships that exist within this setting, was beneficial in the development of questions for the interviews, and was valuable in terms of knowing what probes to insert during the interview process, but may have influenced the way in which the researcher reviewed and interpreted the data. Because the researcher experienced a wide range of interaction with parents and was unsure what components of parent-therapist

interaction contributed to collaboration, and because the researcher has not worked in Ontario and was not familiar with how parent-therapist interactions occur here, the researcher tried to be as objective as possible in the analysis of the data.

Future Research & Recommendations

Parents, therapists, and senior level staff all have voices that need to be heard. Being aware of each other's perspective and informing management of the collective concerns of each group can establish a framework for open communication and effective service delivery. The present study provided participants with an opportunity to share their views in a comfortable and inviting setting. All individuals contacted expressed interest in participating and many, parents especially, informed the researcher that this was a worthy topic of interest and one that certainly needed to be discussed. From the experiences shared, it was determined that there are few opportunities for all team members to interact and that parent-therapist interaction is clouded by uncertainty about what is professional and what is not and by potentially mismatched expectations between what the job description mandates and how parents and therapists would like to interact. Becoming aware of these discrepancies, as well as hearing about the strategies that have been working can inform current practice.

Specific recommendations derived from the results of this study include: 1) Clearly outlining and routinely reviewing the roles and expectations of each team member to address Role Definition and Consistency, 2) interactive training sessions for ITs and parents on a) Perspective-Taking/Empathy, b) building rapport (Trust) and maintaining a professional, but understanding relationship with one another, c) important information to communicate to team members and how to encourage Open Communication, and d) respecting parent/client privacy and 3) Create a support group, provide a venue, or refer parents and staff to appropriate services

that provide an opportunity for an open sharing of experiences. Numerous parents expressed feeling a need to discuss emotional issues with therapists. If the therapist is unable to provide this support within his or her role, it would be helpful for both parents and therapists to know what other support is available and what to do in these situations. ITs could also benefit from sharing strategies that have been successful for them when interacting with parents and from having an outlet for discussing emotional issues that may not be appropriate to discuss with parents.

An additional recommendation includes encouraging agencies to hold their own forums to examine what issues are important to each individual and to discuss how the team can work together to improve parent-therapist collaboration. The present study, for example, could be replicated on a smaller scale within an agency. Management could arrange an opportunity for parents and ITs to meet and discuss their perspectives on parent-therapist collaboration. Such a forum would provide insight to management on the concerns of their clients' families and employees and perhaps uncover common themes that could be addressed in training workshops.

The hierarchical structure of the IBI setting presents a complex environment for investigation. The wide variety of concepts mentioned and discussed at length within each interview highlights the need for more research to be conducted within this setting. Future research can be approached in two ways: on a larger and broader scale – targeting a larger sample and wider demographic (e.g., greater geographical area, including male therapists and fathers, including participants with different cultural backgrounds) or on a smaller, more intensive scale – targeting the stakeholders of one setting and conducting several interviews with the same group. Both have theoretical and practical applications. A larger study would contribute to the field by providing an overall understanding of parent-therapist dynamics in IBI settings

and could generate, much like the intent of this study, suggestions that could be implemented at a regional or an agency level.

A more intensive study of one specific setting could provide a detailed account of how parent-therapist collaboration occurs in that setting and factors that can be altered or improved which will directly affect the current clientele. A private agency would likely be a good place to start this type of research as ST 2 herself mentioned, “I can go back to my agency today and say yeah I’m going to implement this...and we talk about how best to implement it and we get the staff on board” (ST Interview 1, p. 12) or even within a team at a regional program because ST 1 mentioned that it is pretty easy to implement mini-trainings within a team (p. 13). Focusing on one team at one agency would enable a researcher to first consult all members of the team (parents included) about their perceived barriers to collaboration and things they would like to see improved and design a training module that addresses the modifiable needs (e.g., defining each member’s role, practicing perspective-taking scenarios) and a support group to provide an outlet for sharing experiences about concerns that cannot be changed or addressed immediately. An evaluation of the impact of this approach on parent involvement and parent-therapist collaboration could provide further support for the need to examine these issues at a region-wide level.

While this study did not focus on child outcomes of IBI or parent satisfaction with services, it is not surprising that parents and therapists had experiences to share that sometimes reflected this topic more than parent-therapist collaboration. Grindle, Kovshoff, Hastings, and Remington (2009) point out in a recent study they conducted to look at parent experiences in home-based ABA programs for children with autism, that more research has been focused on child outcomes in EIBI than on the impact on the family. The narratives shared by participants

about parents having to “...rearrange their life to have their child in IBI” (Therapist 7, Therapist Interview, p. 8) and quitting their jobs to accommodate IBI (Parent 3, Parent Interview 2, p. 6) confirmed the need to focus more efforts on determining the changes parents go through and the impact that these changes have on the family.

Finally, two secondary interests of the researcher for this study were to examine the effects of setting (home or center) on parent-therapist collaboration, as well as differences in strategies for collaboration in privately operated programs or regional programs. As the study unfolded it became apparent that this was too wide a scope of interest, but based on the responses spontaneously provided by participants (in combination with the decision of regional agencies not to collaborate with the researcher), one that needs to be investigated in further detail. STs repeatedly referred to how much more restricted parent-therapist collaboration is in center settings because typically the parents just drop their children off and then pick them up after the session. The considerations surrounding a stranger entering a family’s home and how to provide support in this context for both the IT and the family would be helpful to address in further detail.

In reference to how different strategies for collaboration may be used in private programs compared to regional programs, a better understanding of how and why different strategies are being used and which are most effective could be examined. Currently there seems to be a lot of general confusion regarding the differences between these two types of programming and misconceptions as to what is possible to do in one program over the other.

ITs seemed to think a distinction between private and regional services needed to be made. During the open-ended opportunity at the end of the interview to add anything else, Therapist 2 raised the following: “It’s interesting with the private though, right? Like the private

though would be a whole different ball of wax. Because private is just like, oh man, it's almost liberating!" (Therapist Interview, p. 21). Therapist 7 agreed suggesting that was an important point to include and, because the researcher had not asked the participants to indicate what type of program they worked for, proceeded to ask if everyone who participated was regional. Several ITs expressed surprise and disbelief that one of the participants in the focus group worked for a private agency (e.g., Therapist 2: "You were private?! Holy smokes!", p. 21), suggesting a need to pursue this subject to a further extent. STs and ITs are an important source of information for parents. Defining the goals and objectives of these programs and making them known to STs and ITs would be a step toward dispelling potentially harmful myths that could influence what type of service a parent pursues for their child or the expectations parents have for the services they do choose.

Conclusion

The discussions held for this study were a well received outlet for a wide range of service providers and consumers who want to work together for the benefit of the child, but who also have personal needs and desires that influence how this happens. By consulting the individuals who implement and use these services, researchers and service-providers can gain insight into the relative importance of parent-therapist collaboration to each family, as well as the training and support that needs to be provided to their staff to improve these important relationships. The need for clearly defined roles, permitting a middle-ground between personal and professional relationships, and creating supports (or referring individuals to appropriate supports) for needs that may not fall within the scope of IBI, reflect very important issues that can, and should, be addressed for the benefit of the agency, senior level staff, therapists, parents, family, and children.

Parent-therapist collaboration has been recognized as a potential contributing factor to the success of behavioural interventions (Marshall & Mirenda, 2002). Upon completion of this study, the researcher would argue that much work still needs to be done to try to understand how parent-therapist collaboration can be fostered to complement the intervention method that has been accepted for children with autism. A hopeful thread however, that was common in all group discussions, was the realization that they are all on the same side – that “...they [parents and ITs] have similar goals and so to help them see that” (ST 2, ST Interview 2, p. 14) can be a reminder to senior level staff and management that this is a discussion worth having with parents and therapists together.

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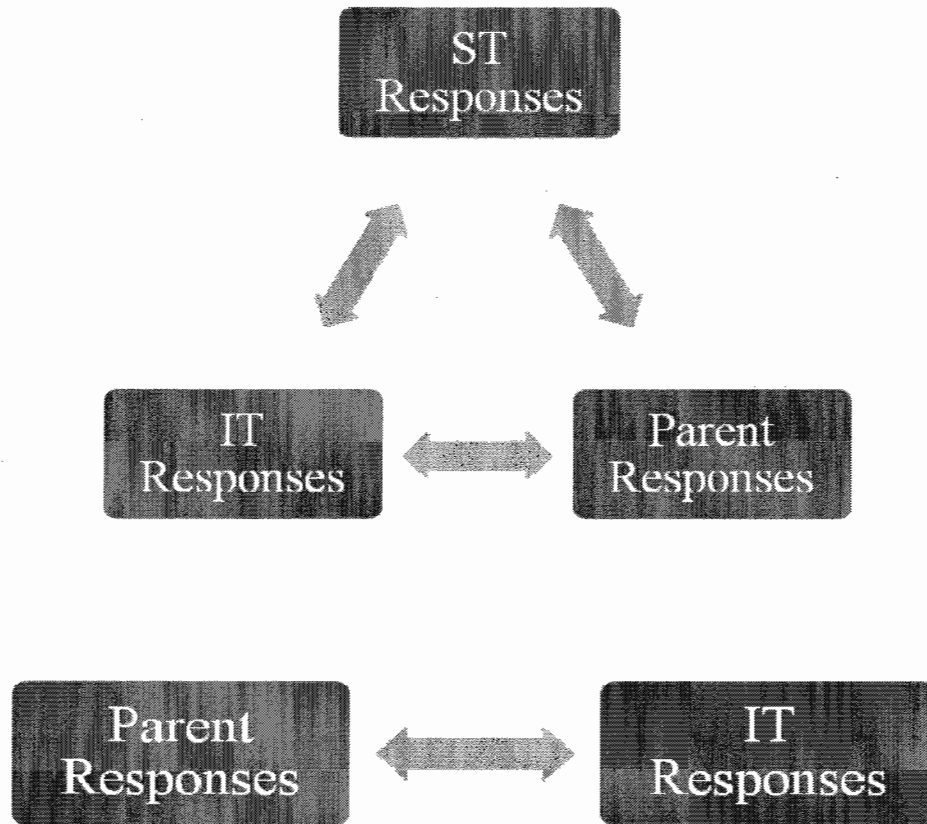
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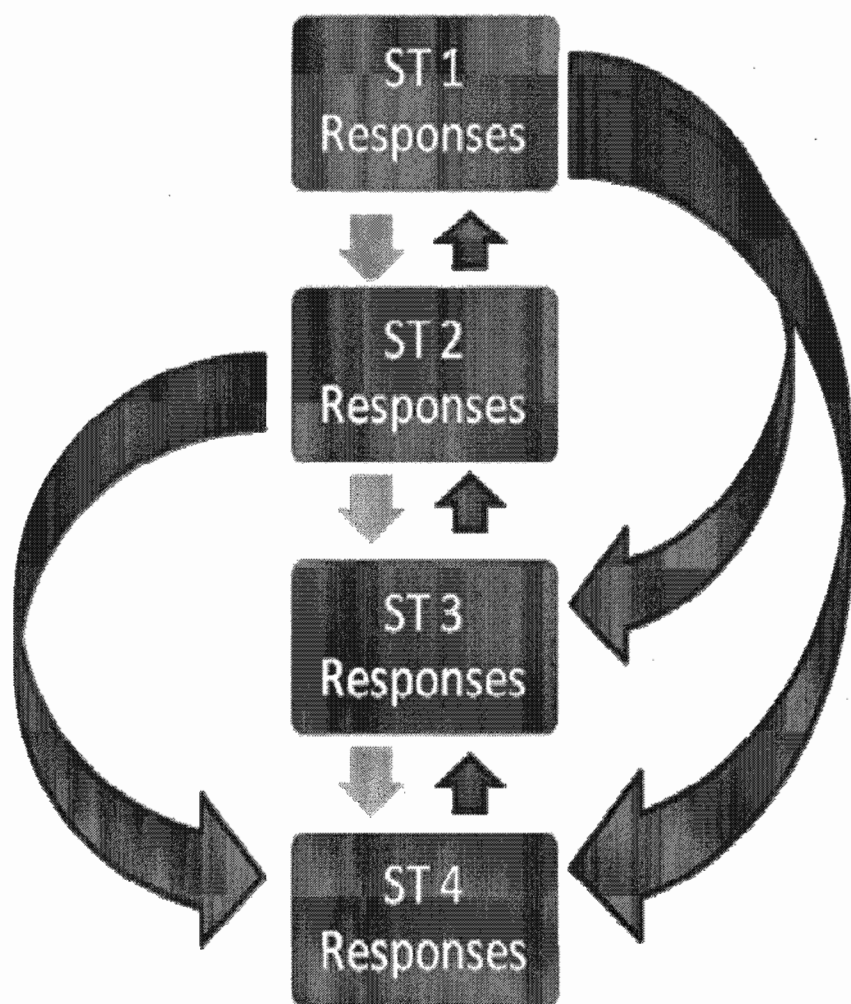
Figure Captions

Figure 1. Cross-case analysis. The researcher compared the responses to each question for each group (STs, ITs, and parents). An additional comparison was made of parent and IT responses.

Figure 2. Within-case analysis. A sample of the comparisons made within the ST group.

Responses from each ST for each question were compared to the responses of all STs interviewed. Similar comparisons were made for the parent and therapist groups.





Appendix A

General Focus Group Script

1. Welcome & Introductions

Welcome and thank you for joining us this morning/evening. I am Melissa MacDonald and I am a Master of Arts student in Applied Disability Studies, this is Dr. Connolly, my faculty supervisor, and this is [insert name] – a research assistant for this project. Let's take a few moments to introduce ourselves around the table. Please introduce yourself with your first name only and let everyone know how long you have received or provided services in IBI.

[Proceed around table until all participants are introduced]

2. Overview of Topic

The purpose of this focus group is to obtain a detailed account of the experiences you have had with parents/therapists and how this has affected the quality of their/your child's services in Intensive Behavioural Intervention (IBI). Such information can be extremely useful for improving interventions for children with autism by incorporating both parent and therapist perspectives. We recognize that you as parents/therapists spend a great deal of time with your child/client and have very important things to say about how to promote collaboration between the two of you for the benefit of the child.

Before we begin discussing your unique experiences it is important to review some ground rules:

3. Ground Rules

We will be on a first name basis during this session but we will not be using any of your names in any written reports. You may be assured of complete confidentiality.

We will honor your time by making sure that we wrap up in the next 90 minutes. The session will be videotaped solely for the purpose of making it easier to transcribe what has been said during the session. We do not want to miss any of the valuable information you provide! If at any time you feel uncomfortable feel free to choose to skip answering a question. You can do so by indicating that you would like to pass.

Keep in mind there are no right or wrong answers to the questions posed, we are just interested in your experiences and opinions. You do not need to agree with others, but please listen respectfully as others share their views. Please refrain from discussing any client, family, or service provider names in order to protect the confidentiality of such persons or organizations. My role is to moderate the discussion. There may be times where I need to encourage other participants to speak more or redirect the focus of a discussion. Please remember that this is in the service of obtaining as much useful information as possible and not meant to offend anyone. If necessary, you may leave to use the washroom or take phone calls that you must respond to. If you do need to answer the phone, you can go to [insert location] so as to minimize disruption to

the conversation. If you do not feel comfortable participating you are under no obligation to continue and can stop participating at any time.

Again, thank you for participating! Are there any questions before we begin?

[Address any questions]

4. Begin questions

Note: The student researcher has previously sat in as an approved observer on other focus groups of parents with children with autism and thus has some experience regarding formulation of questions.

SUPERVISOR FOCUS GROUP QUESTIONS

1. Describe your relationship with a client's parents.
Probes: face time, generalization, rapport, interaction
2. Describe Instructor Therapist and parent interactions
3. How often and how important are interaction between parents and ITs?
Probes: daily, weekly, monthly, very, not, unproductive, useful
4. What opportunities for parent involvement exist in your service?
Probes: training, social activities, meetings, homework
5. What opportunities for ITs exist within your organization for ITs to be trained in parent training?
Probes: staff training, parent training, extended learning, workshops
6. How involved are the parents of your clients in what is daily therapy?
Probes: homework, log books, parent training, parent meetings
7. How involved are the ITs of your clients in promoting collaboration between the therapy and home settings?
Probes: homework, log books, parent training, programming, case meetings
8. What do you see as the barriers to open communication and conflict resolution when there are upsets or disagreements between parents and instructor therapists?
9. What factors interfere with collaboration between parents and ITs?
Probes: time, knowledge/experience, encouragement, support, opportunity
10. What can you as supervisor do to improve collaboration between parents and ITs?
11. What can an IT do to improve collaboration between parents and ITs?

12. What can parents do to improve collaboration between parents and ITs?
13. What can your agency do to improve collaboration between parents and ITs?
14. Of all the things we discussed, what to you is the most important way to improve collaboration?

PARENT ONLY FOCUS GROUP QUESTIONS

1. Describe your role in your child's IBI program.
2. Describe your relationship with your child's Instructor Therapists.
Probes: face time, generalization, rapport, interaction
3. Describe parent and Instructor Therapist interactions
4. How often would you like / how important is interaction with your child's ITs?
Probes: daily, weekly, monthly, very, not, unproductive, useful
5. What opportunities for parent involvement exist in your IBI program?
Probes: training, social activities, meetings, homework
6. What type of training do you receive in order to help with generalization from therapy to home/community?
7. What do you look for in an IT? Take a piece of paper and jot down three things that are important to you in an IT.
Probes: characteristics, experience
8. What do you think your child's ITs' expectations are of you?
Probes: homework, generalization, involvement, programming, communication
9. Tell me about positive experiences you have had with your child's ITs?
10. Tell me about disappointments you have had with your child's ITs?
11. What factors/barriers interfere with collaborating with your child's IT?
Probes: time, knowledge/experience, encouragement, support, opportunity
12. How could you help to improve parent-therapist collaboration?
Probes: scheduled meetings, training, communication log book
13. What can the IT do to improve parent-therapist collaboration?

14. What can the agency do to improve parent-therapist collaboration?
15. Of all the things we discussed, what to you is the most important?

THERAPIST ONLY FOCUS GROUP QUESTIONS

1. Describe your relationship with your client's parents.
Probes: face time, generalization, rapport
2. How important is interaction with your child's IT?
Probes: daily, weekly, monthly, very, not, unproductive, useful
3. How might you suggest improving this relationship?
4. What are your expectations of your client's parents?
5. What characteristics do you look for in parents? Take a piece of paper and jot down three things that are important to you regarding parent involvement.
6. What do you think your ITs' expectations are of you?
7. What can you do to improve collaboration between the parents and yourself?
8. What can the parents do?
9. What can the agency do?
10. Tell me about positive experiences you have had with your client's parents?
11. Tell me about disappointments you have had with your client's parents?
12. What opportunities for parent involvement exist?
Probes: training, social activities, meetings, homework
13. How involved are the parents of your clients in what is happening in therapy?
Probes: homework, log books, parent training, parent meetings
14. Of all the things we discussed, what to you is the most important?

5. Conclusion

- a. Summarize with confirmation
- b. Review purpose and ask if anything has been missed
- c. Thanks and dismissal

Appendix B

Parent Demographics Questionnaire

Instructions: Please answer the following questions as completely and honestly as you can. This information is STRICTLY CONFIDENTIAL – do not write your name anywhere on this page. Thank you for your cooperation!

1. Gender _____
2. Race/ethnicity _____
3. Highest year of school completed _____
4. Relationship status _____
5. Number of people in household _____
6. Number of children in household _____
7. Number of children receiving services _____
8. Child's diagnosis _____
9. Age(s) of children receiving services _____
10. Relation to child receiving services _____
11. Number of years child received services _____
12. Please list the types of services your child has received:

13. Have you participated in parent training? _____

If so, please provide some detail on how useful this training was to you:

14. Please provide an estimate of the amount of time in minutes that you interact with your child's Instructor Therapist per week: _____

15. Are you given IBI programming to complete with your child (e.g., generalization) at home or in the community? _____

If yes, are you able to complete this? Why or why not?

Thank you for your cooperation! ☺

Appendix C

Supervisor & Therapist Demographics Questionnaire

Instructions: Please answer the following questions as completely and honestly as you can. This information is STRICTLY CONFIDENTIAL – you do not have to write your name anywhere on this page. Thank you for your cooperation!

1. Gender _____
2. Age _____
3. Race/ethnicity _____
4. Highest year of school completed _____
5. Current job title _____
6. Number of years you have been a Supervisor/Senior Therapist _____
7. Please list any additional training you have received:


8. Have you ever participated in a parent training program? _____
9. Please provide an estimate of the amount of time in minutes that you interact with a client's parents each day:

10. Do you send IBI programming or homework home for parents to complete? _____

Appendix D

Recruitment Ad

Discuss **YOUR** experiences in IBI with other parents and service providers!



**Parent-Therapist Collaboration in
IBI: Strategies to Promote
Teamwork**

SUPERVISORS

If you are a Supervisor or Senior Therapist who has been supervising for a minimum of 2 years in an IBI program, you are invited to participate in one 90 minute focus group to discuss parent-therapist interaction.

INSTRUCTOR THERAPISTS

If you are an IT who has been working for a minimum of 6 months in an IBI program, you are invited to participate in 2 focus groups to discuss experiences you have had with your client's parents.

PARENTS

If your child with autism has been receiving IBI in your home or at a center for 3 months or more, you are invited to participate in 2 focus groups to discuss experiences you have had with your child's Instructor Therapist.

PARTICIPATION INCLUDES:

- A short demographics questionnaire
- One or two 90 minute focus groups at Brock University

Refreshments will be provided!

If interested please contact:

Melissa MacDonald	Dr. Maureen Connolly
MA Candidate in Applied Disability Studies	Faculty Supervisor
Brock University, St. Catharines, ON	Brock University
mm08dl@brocku.ca	St. Catharines, Ontario
905-941-3356	905-688-5550 Ext. 3381

This study has been reviewed and received ethics clearance through Brock University's Research Ethics Board (File #08-365).

Appendix E

Camp Director Letter of Permission



Brock University

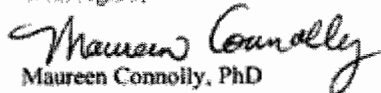
St. Catharines, Ontario, Canada L2S 3A1 Telephone (416) 688-5550 Fax (416) 688-2789

To: whom it may concern
From: Maureen Connolly, Ph.D., Professor, PEKN; Coordinator, Autism Spectrum
Disorder (ASD) Movement Camp
Regarding: permission to attend and utilize camp context for research

Please accept this memo as my permission for Melissa MacDonald to attend all curricular components of the ASD summer movement camp, August 2009, for purposes of data collection for her Master's thesis, and to have supervised access to movement profiles and camp records.

I am confident that Ms. MacDonald's research will strengthen approaches to pedagogy appropriate to this population and is consistent with the research that I have been conducting in my camp context for the past decade.

With regard,


Maureen Connolly, PhD
Professor, PEKN

Appendix F

General Statement of Confidentiality (Research Assistants)

Name of Research Assistant/Transcriber:

**Promoting Parent-Therapist Collaboration in Intensive Behavioural Intervention
Programs: Exploring Strategies to Improve Teamwork**

An important part of conducting research is having respect for privacy and confidentiality. In signing below, you are agreeing to respect the participant's right to privacy and that of the people and organizations that may be included in the information collected. Such information may include interviews, questionnaires, diaries, audiotapes, and videotapes. You are asked to respect people's right to confidentiality by not discussing the information collected in public, with friends or family members. The study and its participants are to be discussed only during research meetings with the Principal Investigators, Co-Investigators, Program Manager, and/or others identified by the Investigators.

In signing below, you are indicating that you understand the following:

- I understand the importance of providing anonymity (if relevant) and confidentiality to research participants.
- I understand that the research information may contain references to individuals or organizations in the community, other than the participant. I understand that this information is to be kept confidential.
- I understand that the information collected is not to be discussed or communicated outside of research meetings with the Principal Investigators, Co-Investigators or others specifically identified by the Investigators.
- When transcribing audio or videotapes (where applicable), I will be the only one to hear the tapes and I will store these tapes and transcripts in a secure location at all times.
- I understand that the data files (electronic and hard copy) are to be secured at all times (e.g., not left unattended) and returned to the Principal Investigator when the transcription process is complete.

In signing my name below, I agree to the above statements and promise to guarantee the anonymity (if relevant) and confidentiality of the research participants

Signature of Research Assistant/Transcriber: _____

Date: _____

Appendix G

Supervisor Informed Consent Form

Date: January 20, 2010

Project Title: Promoting Collaboration in Intensive Behavioural Intervention Programs: Exploring Strategies to Improve Teamwork

Principal Investigator: Melissa MacDonald, MA student
Center for Applied Disability Studies
Brock University
(905) 941-3356; mm08di@brocku.ca

Faculty Supervisor: Dr. Maureen Connolly
Department of Physical Education & Kinesiology
Brock University
(905) 688-5550 Ext. 3381; mconnolly@brocku.ca

INVITATION

You are invited to participate in a study that involves research. The purpose of this study is to obtain a detailed qualitative account of the experiences parents and therapists have had with one another and how this has affected the quality of their child's services in Intensive Behavioural Intervention (IBI). Such information can be used to improve intervention for children with autism by incorporating both parent and therapist perspectives.

WHAT'S INVOLVED

As a participant, you will be asked to complete a short demographics questionnaire and participate in one 90 minute focus group. This focus group will consist of you and one-two other Supervisors who supervise Instructor Therapists providing one-on-one therapy to children with autism receiving IBI. The researcher will introduce the other participants and moderate a discussion about your experiences with the parents of a client with autism and how collaboration between therapists and parents may be improved. The session will be video recorded to enable the researcher to transcribe the discussion in as much detail as possible. Refreshments will be provided. In total, participation will take approximately two hours of your time.

POTENTIAL BENEFITS AND RISKS

Possible benefits of participation include having the opportunity to share your experiences in a setting in which you are respected and you will feel comfortable sharing your perspective. The overarching goal of this study is to investigate ways in which relationships between parents and therapists may be improved. As a Supervisor you have the opportunity to interact with both parent and therapists and your feedback on how collaboration can be improved will be very useful. Specifically the information you provide may be helpful in the formulation of questions to be asked of parents and therapists in later focus group sessions of this study. There also may be risks associated with participation. It is possible that you or other participants may raise concerns about the degree of involvement each has in the programming for the child or the expectations each has for the other that may be upsetting. If at any time you are uncomfortable, you are permitted to leave or refrain from answering the question.

CONFIDENTIALITY

All information you provide will be considered confidential and grouped with responses from other participants. Given the format of this session, we ask you to respect your fellow participants by keeping all information that identifies or could potentially identify a participant and/or his/her comments confidential.

Data collected during this study will be stored in a locked filing cabinet at Brock University. Data will be kept for the duration of the study (one year) after which all written records and videotape will be destroyed and disposed of. Access to this data will be restricted to Melissa MacDonald and Dr. Maureen Connolly.

VOLUNTARY PARTICIPATION

Participation in this study is voluntary. If you wish, you may decline to answer any questions or participate in any component of the study. Further, you may decide to withdraw from this study at any time and may do so without any penalty or loss of benefits to which you are entitled.

PUBLICATION OF RESULTS

Results of this study may be published in professional journals and presented at conferences. Feedback about this study will be available from Melissa MacDonald (mm08dl@brocku.ca) or Dr. Maureen Connolly (mconnolly@brocku.ca) approximately one month after the final focus group.

CONTACT INFORMATION AND ETHICS CLEARANCE

If you have any questions about this study or require further information, please contact the Principal Investigator or the Faculty Supervisor (where applicable) using the contact information provided above. This study has been reviewed and received ethics clearance through the Research Ethics Board at Brock University (File # 08-365). If you have any comments or concerns about your rights as a research participant, please contact the Research Ethics Office at (905) 688-5550 Ext. 3035, reb@brocku.ca.

Thank you for your assistance in this project. Please keep a copy of this form for your records.

CONSENT FORM

I agree to participate in this study described above. I have made this decision based on the information I have read in the Information-Consent Letter. I have had the opportunity to receive any additional details I wanted about the study and understand that I may ask questions in the future. I understand that I may withdraw this consent at any time.

Name: _____

Signature: _____ Date: _____

Appendix H

Parent Informed Consent Form

Date: February 21, 2010

Project Title: Promoting Collaboration in Intensive Behavioural Intervention: How to Change the 'Parents vs. Therapists' Dichotomy to 'Parents & Therapists'

Principal Investigator: Melissa MacDonald, MA student
Department of Applied Disability Studies
Brock University
(905) 941-3356; mm08dl@brocku.ca

Faculty Supervisor: Dr. Maureen Connolly
Department of Physical Education & Kinesiology
Brock University
(905) 688-5550 Ext. 4707; mconnolly@brocku.ca

INVITATION

You are invited to participate in a study that involves research. The purpose of this study is to obtain a detailed qualitative account of the experiences parents and therapists have had with one another and how this has affected the quality of your child's services in Intensive Behavioural Intervention (IBI). Such information can be used to improve intervention for children with autism by incorporating both parent and therapist perspectives.

WHAT'S INVOLVED

As a participant, you will be asked to complete a short demographics questionnaire and participate in two 90 minute focus groups. The first focus group will consist of you and five other parents who have children with autism receiving IBI. The researcher will introduce the other participants and moderate a discussion about your experiences with your child's Instructor Therapist. The session will be video recorded to enable the researcher to transcribe the discussion in as much detail as possible. A month later you will be invited to participate in a second focus group that consists of the same group as your first session and an additional six participants who are current Instructor Therapists. The moderator will lead a discussion about your experiences together and how collaboration between parents and therapists may be improved. Refreshments will be provided. In total, participation will take approximately five hours of your time.

POTENTIAL BENEFITS AND RISKS

Possible benefits of participation include having the opportunity to share your experiences in a setting in which you are respected and you will feel comfortable sharing your perspective. The overarching goal of improving the relationships between parents and therapists may also begin to occur in the combined focus group as you both learn of each others' perspective and how you might support each other in the future. There also may be risks associated with participation. It is possible that, in the Combined: Parents + Therapists focus group, you or other participants may raise concerns about the degree of involvement each has in the programming for the child or the expectations each has for the other that may be upsetting. If at any time you are uncomfortable, you are permitted to leave or refrain from answering the question. In the event that a matched pair between a therapist and parent is present in the same group, a protocol will be followed to minimize the possibility that personal information will be shared with the group.

CONFIDENTIALITY

All information you provide will be considered confidential and grouped with responses from other participants. Given the format of this session, we ask you to respect your fellow participants by keeping all information that identifies or could potentially identify a participant and/or his/her comments confidential.

Data collected during this study will be stored in a locked filing cabinet at Brock University. Data will be kept for the duration of the study (one year) after which all written records and videotape will be destroyed and disposed of. Access to this data will be restricted to Melissa MacDonald and Dr. Maureen Connolly.

VOLUNTARY PARTICIPATION

Participation in this study is voluntary. If you wish, you may decline to answer any questions or participate in any component of the study. Further, you may decide to withdraw from this study at any time and may do so without any

penalty or loss of benefits to which you are entitled. Withdrawal from this study or your level of participation in the focus group sessions will have no negative impact on the treatment that your child receives.

PUBLICATION OF RESULTS

Results of this study may be published in professional journals and presented at conferences. Feedback about this study will be available from Melissa MacDonald (mm08dl@brocku.ca) or Dr. Maureen Connolly (mconnolly@brocku.ca) approximately one month after the final focus group.

CONTACT INFORMATION AND ETHICS CLEARANCE

If you have any questions about this study or require further information, please contact the Principal Investigator or the Faculty Supervisor (where applicable) using the contact information provided above. This study has been reviewed and received ethics clearance through the Research Ethics Board at Brock University (REB File #08-365). If you have any comments or concerns about your rights as a research participant, please contact the Research Ethics Office at (905) 688-5550 Ext. 3035, reb@brocku.ca.

Thank you for your assistance in this project. Please keep a copy of this form for your records.

CONSENT FORM

I agree to participate in this study described above. I have made this decision based on the information I have read in the Information-Consent Letter. I have had the opportunity to receive any additional details I wanted about the study and understand that I may ask questions in the future. I understand that I may withdraw this consent at any time.

Name: _____

Signature: _____ Date: _____

Appendix I

Therapist Informed Consent Form

Date: February 8, 2010

Project Title: Promoting Collaboration in Intensive Behavioural Intervention: How to Change the 'Parents vs. Therapists' Dichotomy to 'Parents & Therapists'

Principal Investigator: Melissa MacDonald, MA student
Department of Applied Disability Studies
Brock University
(905) 941-3356; mm08dl@brocku.ca

Faculty Supervisor: Dr. Maureen Connolly
Department of Physical Education & Kinesiology
Brock University
(905) 688-5550 Ext. 4707; mconnolly@brocku.ca

INVITATION

You are invited to participate in a study that involves research. The purpose of this study is to obtain a detailed qualitative account of the experiences parents and therapists have had with one another and how this has affected the quality of their child's services in Intensive Behavioural Intervention (IBI). Such information can be used to improve intervention for children with autism by incorporating both parent and therapist perspectives.

WHAT'S INVOLVED

As a participant, you will be asked to complete a short demographics questionnaire and participate in two 90 minute focus groups. The first focus group will consist of you and five other Instructor Therapists who provide one-on-one therapy to children with autism receiving IBI. The researcher will introduce the other participants and moderate a discussion about your experiences with the parents of a client with autism. The session will be video recorded to enable the researcher to transcribe the discussion in as much detail as possible. A month later you will be invited to participate in a second focus group that consists of the same group as your first session and an additional six participants who are parents of children with autism. The moderator will lead a discussion about your experiences together and how collaboration between therapists and parents may be improved. Refreshments will be provided. In total, participation will take approximately five hours of your time.

POTENTIAL BENEFITS AND RISKS

Possible benefits of participation include having the opportunity to share your experiences in a setting in which you are respected and you will feel comfortable sharing your perspective. The overarching goal of improving the relationships between parents and therapists may also begin to occur in the combined focus group as you both learn of each others' perspective and how you might support each other in the future. There also may be risks associated with participation. It is possible that, in the Combined: Parents + Therapists focus group, you or other participants may raise concerns about the degree of involvement each has in the programming for the child or the expectations each has for the other that may be upsetting. If at any time you are uncomfortable, you are permitted to leave or refrain from answering the question. In the event that a matched pair between a therapist and parent is present in the same group, a protocol will be followed to minimize the possibility that personal information will be shared with the group.

CONFIDENTIALITY

All information you provide will be considered confidential and grouped with responses from other participants. Given the format of this session, we ask you to respect your fellow participants by keeping all information that identifies or could potentially identify a participant and/or his/her comments confidential.

Data collected during this study will be stored in a locked filing cabinet at Brock University. Data will be kept for the duration of the study (one year) after which all written records and videotape will be destroyed and disposed of. Access to this data will be restricted to Melissa MacDonald and Dr. Maureen Connolly.

VOLUNTARY PARTICIPATION

Participation in this study is voluntary. If you wish, you may decline to answer any questions or participate in any component of the study. Further, you may decide to withdraw from this study at any time and may do so without any penalty or loss of benefits to which you are entitled.

PUBLICATION OF RESULTS

Results of this study may be published in professional journals and presented at conferences. Feedback about this study will be available from Melissa MacDonald (mm08dl@brocku.ca) or Dr. Maureen Connolly (mconnolly@brocku.ca) approximately one month after the final focus group.

CONTACT INFORMATION AND ETHICS CLEARANCE

If you have any questions about this study or require further information, please contact the Principal Investigator or the Faculty Supervisor (where applicable) using the contact information provided above. This study has been reviewed and received ethics clearance through the Research Ethics Board at Brock University (REB File #08-365). If you have any comments or concerns about your rights as a research participant, please contact the Research Ethics Office at (905) 688-5550 Ext. 3035, reb@brocku.ca.

Thank you for your assistance in this project. Please keep a copy of this form for your records.

CONSENT FORM

I agree to participate in this study described above. I have made this decision based on the information I have read in the Information-Consent Letter. I have had the opportunity to receive any additional details I wanted about the study and understand that I may ask questions in the future. I understand that I may withdraw this consent at any time.

Name: _____

Signature: _____ Date: _____

Appendix J

Feedback to Participants

Dear Participant,

Thank you for participating in the research study entitled Promoting Parent-Therapist Collaboration in Intensive Behavioural Intervention Programs: Exploring Strategies to Improve Teamwork. Your participation was essential in the implementation of this study. We want to thank you for allowing us to videotape the focus group discussions, as these discussions provided us with valuable information that allowed us to gain a deeper understanding of parent-therapist relationships. The research team appreciates all of your cooperation and support.

As per your request I have attached a summary of research findings that were taken from each focus group session. We hope that this information is useful for you and your child's therapist.

Feel free to contact my faculty supervisor or myself at any time if you have questions or concerns.

Thank you,

Sincerely,

Melissa MacDonald

Melissa MacDonald, BA
MA Candidate, Applied Disability Studies
(905) 941-3356
mm08dl@brocku.ca

Maureen Connolly, Ph.D
Professor (Faculty Supervisor)
(905) 688-5550 ext. 4707
mconnolly@brocku.ca